

**A SOCIO-CULTURAL STUDY OF LEPROSY IN NEPAL:
Compliance, Patient Illness Career Patterns and Health Education**

by

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This thesis contains no material which has been accepted for the award of any other higher degree or graduate diploma in any tertiary institution, and to the best of my knowledge and belief it contains no material previously published or written by another person, except when due reference is made in the text of the thesis.

J. Hyland
28 May 1993

ABSTRACT

A SOCIO-CULTURAL STUDY OF LEPROSY IN NEPAL: Compliance, Patient Illness Career Patterns and Health Education.

To understand leprosy in Nepal and its social consequences it is important to see it in context. The socio-cultural factors involved in belief systems which surround everyday life are essential to understanding, as well as those of geography and economics, of infrastructure and services, as they all affect the feasibility of travel to clinics.

Patient persistence or "drop out" from clinic as part of their illness "career" is a phenomenon which merits study. This research examines the proposition, within an existing compliance model, that clinic attendance (a crude measure of compliance) is related to patients' beliefs about their condition being close to the western medical notions of their care-ers; and then seeks socio-cultural factors which may be affecting the willingness and ability of patients to travel to clinic regularly.

To western scientific medicine leprosy is caused by M.leprae in an immune-deficient host and results in physical signs. It is treated with drugs (antibiotic and anti-inflammatory) and other therapies like physiotherapy and surgery. Leprosy services are set up and health workers trained according to this scientific model. Leprosy is controlled by treating sufferers for up to 24 months with multi-drug therapy. "Cure" in terms of this model means reduction or removal of the cause.

The culture of Nepal is underscored by the hierarchical Hindu caste system with notions of ritual purity and practices for maintaining social harmony. Ninety per cent of Nepali people are subsistence farmers living in inter-dependent rural communities. The medical system of Nepal is a complex whole with personalistic, naturalistic and some scientific notions of illness. The concept of one absolute causal energy lies behind the dealing with new and alien ideas by accommodation rather than categorisation which characterises western medicine.

Data discussed in this thesis are derived from 160 responses to a

community questionnaire survey, interviews with 34 patients, 28 health workers and field observation in the clinics. Methods of analysing complex qualitative data have been developed during the research, including a patient career "grid" through which associations between various patient responses are shown.

Beliefs about leprosy are found to be unified but many-faceted: physical, meaning deformity and disability; psychological, leading to depression and even suicide; religious, 'a curse has fallen upon me'; socio-cultural, bringing an obligation to separate or expel the affected person, tantamount to "social death".

Patient experiences of the "illness" of leprosy, the physical aspects, differ widely because of individual variation in immune response to M.leprae. The social integration of people who have had the diagnosis of the "disease" of leprosy is threatened when other people come to know about it. Most patients are discovered to be applying the technique of "silence" and "concealment", a socio-cultural device for keeping matters private in rural communities, in an endeavour to prevent, through avoiding the label of leprosy as "sickness", application of the sanction of social separation or expulsion. If "exposure" seems imminent "swift action" may follow which could be withdrawal from treatment, or from the village with family or alone.

Patients are found to be holding apparently conflicting notions about leprosy which are not associated with persistence or "drop out" from clinic. An association is found between threat of exposure and withdrawal from clinic attendance. The interrelations of social "cure", meaning restoration of social integration, and medical "cure" are explored.

The view of leprosy in its socio-cultural context yields rich insights crucial to the appropriate solving of problems such as non-compliance in leprosy control. Findings emerge which have implications for the shaping of services, the planning of health education and training programmes. They suggest that an ethnomedical or non-ethnocentric approach to health care and education problems in cross-cultural situations is essential.

ACKNOWLEDGEMENTS

I am greatly indebted to the courageous people of Nepal who willingly spent time talking to the research assistants and myself during the conduct of the research project in Pokhara, Nepal from February to December 1990 and during another four month visit from October 1991. They gave their time generously. In this work some of their experiences and struggles are presented in the hope that such revelation will assist others in Nepal who may in the future contract leprosy. For these my Nepali friends and for my colleagues I have written in the Preface a Nepali poem which expresses the essence of this work and have translated it back to English for the readers of this thesis.

This research was funded first through a Scholarship from the University of Tasmania and then through a Public Health Research Training Scholarship awarded by the National Health and Medical Research Council, (NH&MRC) Canberra, Australia. Supporting grants for field work and travel were given by The Leprosy Mission International (TLM) and the American Leprosy Missions Inc. (ALM). Without this assistance this work would not have been possible.

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One of the rewards of conducting such cross-cultural research is the rich friendships made and appreciation of the culture and the

people gained through close partnership with Nepalis who worked as research assistants. In particular I owe a great deal to the dedication, frankness and professional skills of these colleagues: full-time research assistant, Srmt Shanta Maya Shrestha, BPH on secondment from INF, interviewing assistant, Srmt Yashoda Gurung, SRN, community survey research assistants Sri Mukti Ram Sharma and Sri Benji Gurung, defaulter follow-up home visitor and interviewer research assistant Sri Hira Bikram Shahi.

During the time spent in Nepal, a link with Tribhuvan University, Kathmandu through Prof Dr Hon Mathura Shrestha, Minister of Health, His Majesty's [interim] Government of Nepal (HMG/N), and collaboration with Dr Adiga, Chief Public Health, HMG/N, [previous] Chief, Leprosy Services, Nepal were much appreciated.

This work was finally and largely supervised by Assoc Prof Joan Abbott-Chapman, Centre for Education, University of Tasmania. I am extremely grateful for her energetic support, generous time allocation and skill. Previously supervision was by Dr Rupert Maclean, Centre for Education, University of Tasmania and associate supervision by Prof T. Dwyer, Dept. of Community Health, University of Tasmania. In the field Dr Vijaya Shrestha, Kathmandu, Nepal advised. Initial supervision (1988) was by Prof T. Dwyer, then Professor of Community Health, University of Tasmania.

I am also indebted to colleagues at the University of Tasmania who, during 1988 and 1989, and again in 1992 and 1993 during the analysis and writing of the thesis, commented on various chapter drafts. Special thanks to those at the Centre for Education and Department of Community Health, and associates at the Menzies Centre for Population Health Research and colleagues at the Centre for Education.

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Many people have helped in various ways during the completion of this work. Some helped with typing, translating, reading and proof reading, others contributed through practical friendship and encouragement and have made life bearable during the analysis of the data and writing of this thesis. They will understand if I do not name them all individually. To Sue, Julia, Gaynor and Melva particular thanks. They know that I could not have completed this work without their support.

Personally, as a Christian, I see my life and work both dedicated to and a service of God, and acknowledge that working with the people of Nepal with their unique dignity and culture is a special privilege. Through this work I have come to prize personal and corporate humility above the commonly found ego and ethnocentrism of which I was previously not fully aware. If this work achieves nothing else it has brought this enlightenment which is personally highly valued.

PREFACE

मतलब

रोगीका आशा बसीरहुनु समाजमा।
नेपालि व्यक्तिका दुखित कथाबाट यसमा,
तिनिहरु सुरक्षित रहेछन लुकाएमा।
के कुष्ठरोगको रोकबाट छुट्याएमा?
त्यसको अफैलिता बैज्ञानिक औषधिमा।
रोगीका शान्ति हामिहरुका सिकाइमा,
कुष्ठरोगको अर्थ पाइन्छ नेपालको संकृतीमा ।

MEANING

The hope of those with the disease is to remain in society.
From painful personal Nepali stories in here,
it appears their security is in concealment.
Is the restriction of leprosy in social separation?
Its non-infectivity is in scientific medicine!
The peace of those with the disease is in our learning,
The meaning of leprosy is to be found in Nepal's culture.

J. Hyland, May 1993

A SOCIO-CULTURAL STUDY OF LEPROSY IN NEPAL: Compliance, Patient Illness Career Patterns and Health Education

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ILLNESS CAREERS

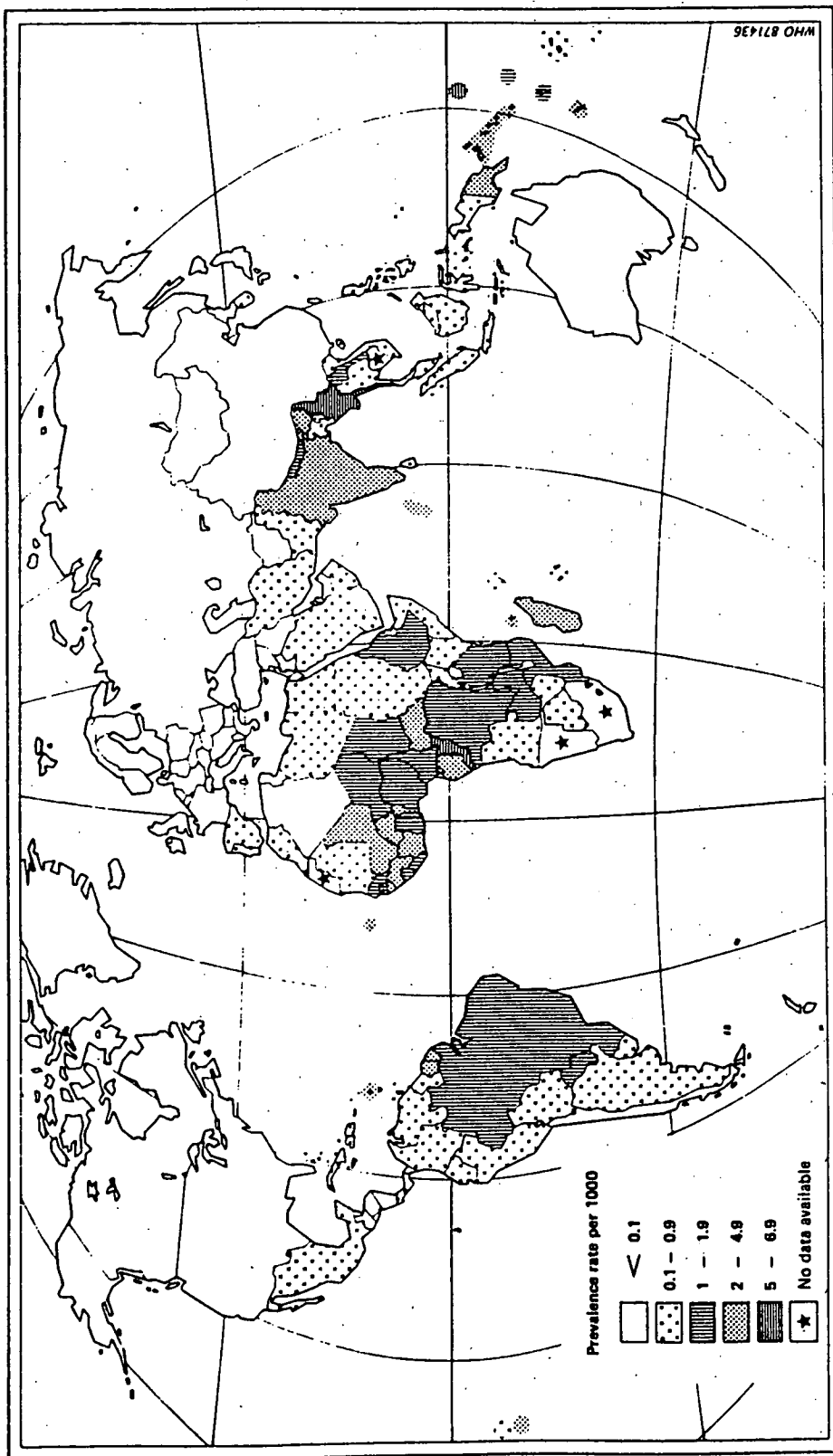
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Prevalence of registered cases of leprosy throughout the world in 1987

CHAPTER 1 : INTRODUCTION

This study is set in the country of Nepal and encounters ancient cultures and people with different ways of viewing their world, including health care strategies. A glimpse of the lives of some of these people is given together with an impression of the effects of leprosy and of western medical care upon them.

This study sets out to understand what leprosy means in Nepal, to examine whether the understandings held by patients relate to their regular attending of clinics for their treatment and to explore whether other factors of a socio-cultural nature may relate to such clinic attendance behaviour.

It is easy to understand the difficulties faced by leprosy patients in seeking and maintaining treatment for their problem in a mountainous country like Nepal with few motor roads, large rivers and few bridges, a monsoon climate and a people living as subsistence farmers.

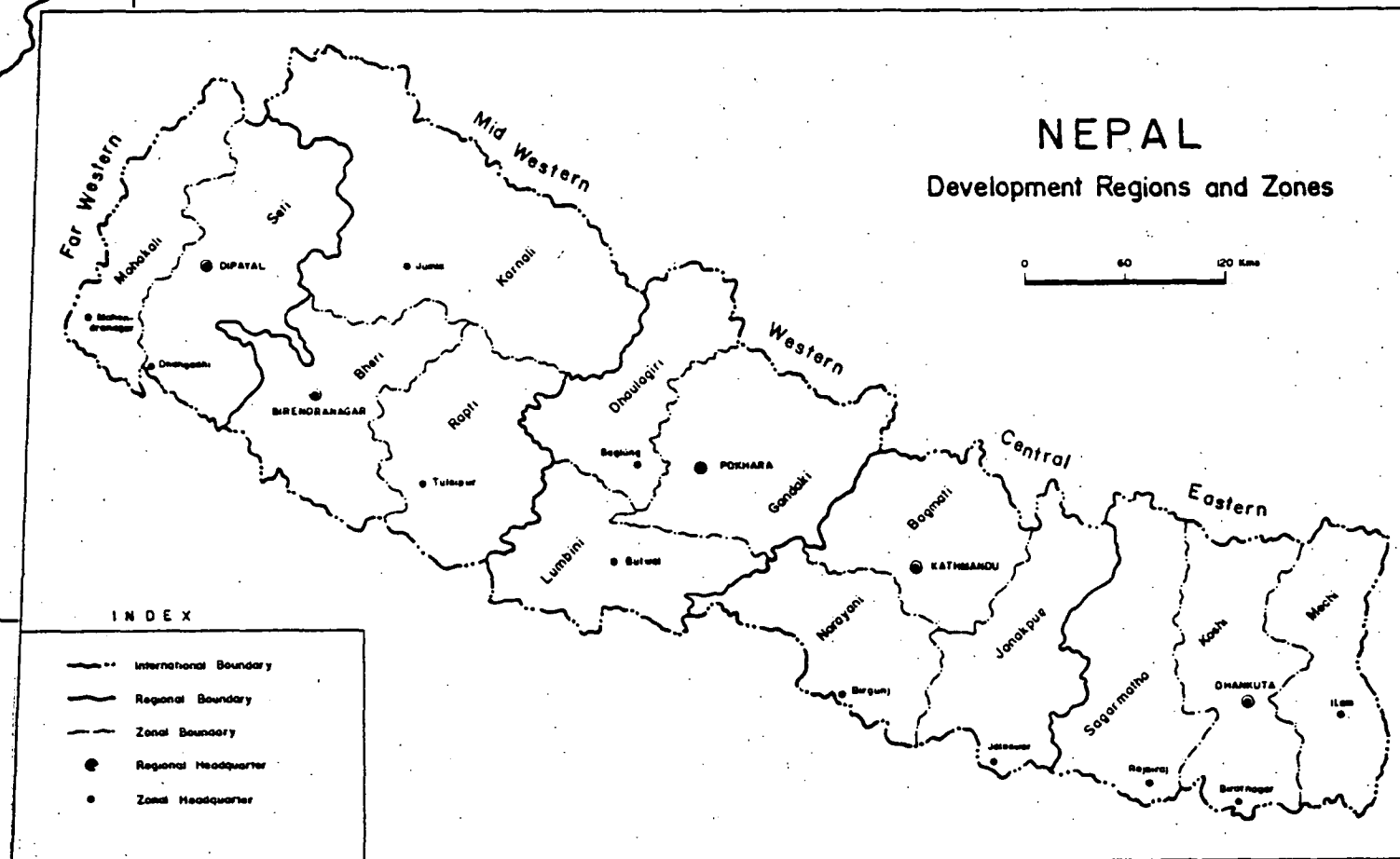
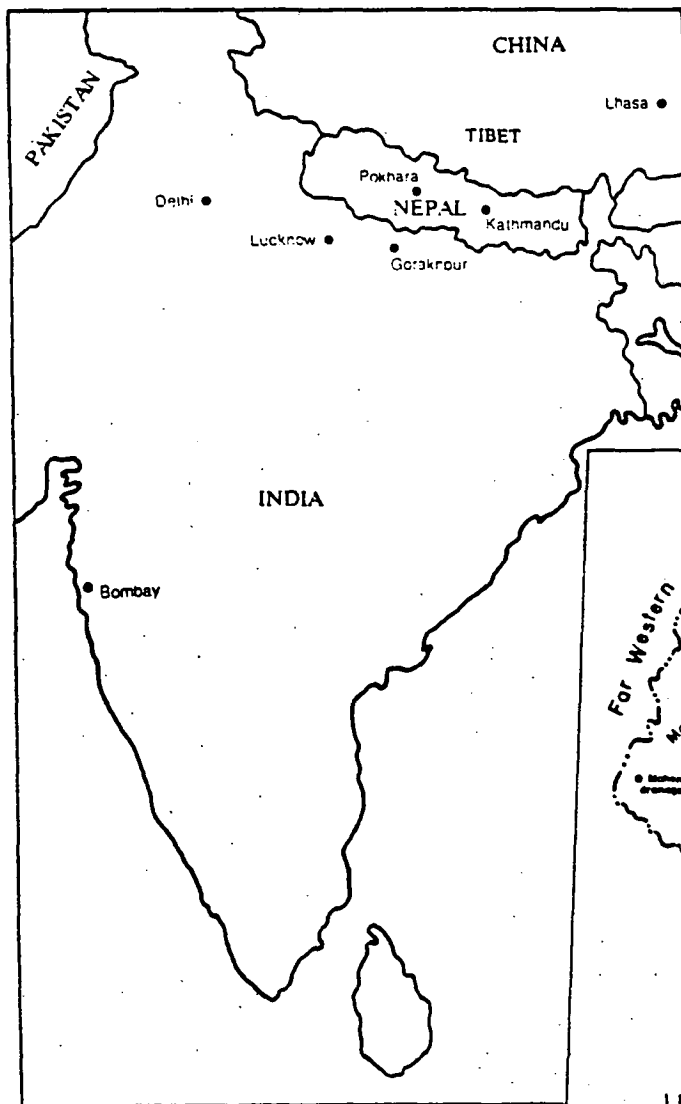
In spite of these difficulties, the majority of patients do continue their long treatment. There are some, however, who begin but then stop attending the clinic regularly, a fact causing concern to public and Leprosy Control administrators.

This study, conducted in 1990 and 1991, focusses on both categories of patient, who received or did not receive treatment from the Out-Patients Department of the Green Pastures Leprosy Hospital in Pokhara, western Nepal.

Studies of leprosy compliance have been conducted in many locations, for instance in India, Pakistan, Thailand, Nepal and Africa. They usually endeavour to identify factors which may relate to patient compliance and non-compliance with a medical regimen, factors which may be amenable to change or manipulation so that compliance improves. A proliferation of compliance studies, both in general in the West and in relation to leprosy in Africa and Asia, speaks to the complexity of, as well as the concern felt about, the problem.

MAP 1.

Nepal in the context
of Asia
(Hawker 1984:6)



No simple easy solution to patient non-compliance has emerged from any of these studies. Many have concentrated on factors associated in turn with the patients; the disease; the treatment regimen; the relationship between patient and practitioner; and so on. Some have looked at patient beliefs with a view to constructing health education programmes aimed at changing these. Advice has been given to simplify and shorten regimens, give clear instructions, improve practitioner communication skills, consider patient convenience for clinic schedules and so on. Some studies in the third world have concluded that there seems to be a cluster of socio-economic and cultural factors which are not clearly understood but which may relate to compliance and non-compliance. Reference to these works will be made in Chapter 2.

While many of the measures suggested emerging from other compliance studies may well help improve compliance in Nepal, there remain socio-cultural factors related to compliance and non-compliance specific to Nepal which as yet are not well understood. This study sought to discover and "tease out" some of these socio-cultural factors specific to the Nepali scene and in the process to extend a particular model of health education planning by using it in a cross-cultural setting.

The author was well placed to undertake such a study, having worked in Nepal since 1969, being fluent in spoken and written Nepali language, and specifically having been responsible for planning and training in the Leprosy Control Programme (LCP) during its formative years, between 1976 and 1982. With this experience and ease of access, the author was therefore enabled to study the process at work from the perspective of a participant observer, using qualitative interpretation and as an objective observer, employing a range of field methods. These are described fully in Chapters 4 and 5.

Systematic leprosy control began in Nepal in 1973/4 and in 1982 the new Multi-Drug Therapy (MDT) was introduced. Leprosy services have been set up and Nepali health workers trained to undertake diagnostic, treatment, monitoring, and education

services across Nepal. These services and training are based upon the scientific medical understanding of the disease of leprosy. It is seen as essentially a physical phenomenon, caused by a bacterium (M. leprae), which varies widely in its manifestation according to the strength and quality of the host immunological response to the organism.

It is thought to be essential that treatment of adequate duration be completed by as many patients as possible (75% or more) to achieve control of the disease in the community (World Health Organisation, 1970, 1975, 1985, 1988). Concern about non-compliance is based on two factors. First, patients who receive intermittent or incomplete therapy may develop bacteria resistant to the drugs. Secondly patients may personally be subject to more complications than they would have been had they completed adequate treatment. Spread of such resistant bacteria to other people can result in new cases with primary resistance. The introduction of MDT was partly motivated by increases in the problem of secondary resistance generally. Compliance is seen to be good for public health and good for the individual patient.

The leprosy services in Nepal exist in the context of the complex culture of Nepal, which is overlaid by the Hindu hierarchical caste system based on concepts of ritual purity and pollution. The practice of social isolation or separation of those ritually polluted (for longer or short periods) is common. Leprosy is regarded as particularly polluting, cursed or "unclean". This is of great relevance to the knowledge of, and reaction to, the presence of leprosy in the community, particularly a close-knit, inter-dependent rural village.

These "western" imported leprosy services, based on scientific medical notions, also exist in the context of Nepal's broad sweep of notions and practices related to illness and cure which make up Nepal's traditional medical system. This system, while knowing and embracing some scientific medical notions, is different in nature and scope from "scientific" medicine. It is underscored by a notion of absolute causal energy with a myriad of manifestations of general misfortune and personal illness. It

is also characterised by an embracing and accommodation of new ideas (such as scientific medicine), thus changing its shape but retaining its integrity and nature and allowing a toleration of apparently conflicting notions of causality and cure.

This kind of accommodation is reflected in findings of this study to be discussed, that beliefs about leprosy held by members of the community and by patients alike are important in helping to explain compliance, non-compliance and patient "return". The notion of leprosy embraced by Nepal includes the physical manifestations with characteristic disabilities and deformities that scientific medicine calls "late case", but further encompasses psychological, religious and socio-cultural meaning, consequences and practices, which this thesis fully explores.

The contrast between scientific and traditional Nepali notions of the origin, meaning and consequences of leprosy also provides the background to differing notions and expectations of cure, both medical and social, which pose challenges to medical practitioners and their methods of health care delivery, and to the design of health education programmes for traditional people.

This study applies a combination of qualitative and quantitative methods, bringing together concepts and models from health education theory, medicine, epidemiology, public health, anthropology and medical sociology in a cross-disciplinary approach to the question of patient compliance in a cross-cultural setting.

The ethnomedical approach of the study to examining the problem of patient compliance and non-compliance in leprosy control in Nepal takes into account both the plurality of Nepal's medical systems and the scientific medical orientation of the planners and practitioners within the leprosy control services in Nepal. Ethnomedicine as defined by Fabrega (1977) is "...the way human groups handle disease and illness in light of their cultural perspective".

The study brings together community views, patient explanations and experiences and health worker explanations and expectations, and then relates these to actual compliance patterns of the patients concerned. It explores the socio-cultural context of leprosy patients' lives and reveals important socio-cultural conventions which are applied in their attempts to retain their social integrity or "health" in the face of a "disease" and "sickness" which carries expectations of strong social sanctions.

First, as a springboard for this field research, a rural Nepali community was surveyed, being a repeat of a survey conducted in 1980. The same interviewer, questionnaire and sampling areas as were used in 1980 were used in 1990. Findings provide a picture of present-day community expectations of leprosy to test consistency over time.

Secondly, the context of the health services, particularly the Leprosy Control Programme and the health workers who provide the health care for the patients were studied in depth. Their notions of leprosy and the consequent structure of the services are described and discussed. A total of 160 responses from four areas is reported.

Thirdly, patients at Green Pastures Leprosy Hospital were studied in 1990 and 1991. This patient study constitutes the major part of the work. It deals with interview material recorded with leprosy patients in Nepal in 1990 and 1991. The main study is made up of 34 interviews. Six others were used for background and case study material.

Fourthly, other small studies were added as the analysis and data gathering proceeded. Some of these were planned ahead, but others suggested themselves out of the interactive and interpretative process of observations and interviews conducted with patients.

This approach to understanding leprosy patients which looks at how they make sense of and attempt to control what is happening to them, yielded insights which are at once a contribution to

theory and at a practical level, are helpful for dealing with the problem defined by western-trained health professionals as patient non-compliance.

Hopefully, thesis outcomes may potentially contribute to the easing of the pain for leprosy patients through:

- (a) Adding to the understanding of health workers who deal with leprosy patients;
- (b) Pointing to more appropriate, culturally informed means of delivering services to leprosy patients;
- (c) Informing the public of what leprosy means to people; and
- (d) Indicating a more solid basis for planning health education.

The thesis presents, as derived from the findings, a new model of leprosy illness careers incorporating scientific and Nepali traditional notions of health and illness, and a related model of a concealment cycle and its place in relation to preservation of patient social integrity and social health and withdrawal from clinic attendance. These are all related to the meaning of leprosy in Nepal and the question of medical and social cure. The importance of restoration to social health as well as physical cure of leprosy patients is underlined by the study, along with exploration of ways in which this might be achieved.

Chapter 2 will introduce in more detail the theoretical concepts used in the thesis reviewing the literature pertaining to the study. Chapter 3 will provide the background to the study. Chapters 4 and 5 discuss research methodology and provide details of the methods used in the study.

Presentation of results begins with the findings of the cohort study of compliance in Chapter 6, leading to a close examination of the context of compliance behaviour in Nepal. The social and medical contexts are outlined in Chapter 7, through a description of medical systems in Nepal and elsewhere. This serves to introduce Chapter 8 which describes community and patient perceptions of leprosy. The background to strong community and patient expectations for leprosy patients to be separated from society is explored in Chapter 9. Contrasting situational

definitions created in the clinics, with the structures and approaches taken by health workers, based on a scientific model of leprosy, are described in Chapter 10. In Chapter 11 the responses of patients, both social and psychological, to having leprosy are presented, along with individual patient illness careers exemplifying categories of patient response to their condition.

Finally in Chapter 12 the relationship between illness careers, progression from "wellness" to illness and beyond, patterns of compliance and non-compliance, degrees of social separation, threatened separation and cycle of concealment are drawn together in a new model for understanding leprosy and patient compliance in Nepal. The implications for patient "cure" and health education in the community are explored.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Introduction

The study constantly crosses disciplinary boundaries, enabling a broader and deeper study of the lives, experiences and responses of people in Nepal who have leprosy, than would be presented by a single disciplinary approach. As the study is cross-disciplinary, it draws on concepts and models from a variety of sources, combining them specifically and uniquely for this thesis. The review of previous work in the field discusses the scholarship, conceptual notions and models chosen as building blocks for the thesis with the thinking behind their choice.

The concepts and models used in this thesis fall into four main categories. Elements from each are drawn upon for the coherent synthesis of a new model which is used to explain the experiences and actions of people with leprosy in Nepal. This chapter discusses key concepts from each of these categories, which constitute the theoretical framework of the thesis.

First, compliance is defined, and models and studies of compliance in general and those related to leprosy and Nepal in particular are reviewed in the light of current research.

Secondly and importantly, selected concepts and models are explored from the social sciences, from medical sociology and anthropology, such as ethnomedicine, world view, medical systems, explanatory models, health, illness, disease, sickness, sickness career, social integration and accommodation, labelling and control, role and status.

Thirdly, notions of health and the model of health education and health promotion used in this study are discussed.

Fourthly, concepts related to scientific bio-medicine such as epidemiology, public health, leprosy and leprosy control are presented.

Compliance

Issues of compliance have puzzled and frustrated health professionals for decades. The very volume of reviews of compliance studies speaks to the complexity of compliance and difficulties encountered in attempting to solve the problem. Hundreds of investigations have been conducted in attempting to discover and to better understand determinants of patient compliance behaviour (Becker 1979:2).

"Compliance" is the term used to describe health behaviour on the part of the patient who follows medical advice. The term "compliance", while carrying with it the unfortunate implication that patients are either passively obedient or wilfully disobedient in the face of medical wisdom (Thompson 1984:110), is used here because it is found extensively in research literature and no widely acceptable alternative has been agreed to.

Early attempts to develop a model which may serve to make sense of the multitude of factors associated with compliance and predict compliance behaviour resulted in the "health belief model" being proposed (HBM) (Rosenstock, 1966; Becker, 1974) (Figure 2:1 p.38) This psycho-social model hypothesises that

... persons will generally not seek preventive care ... unless they possess minimal levels of ... knowledge and motivation, view themselves as potentially threatened and the condition as serious, are convinced of the efficacy of the intervention, and see few difficulties in undertaking the recommended action (Becker 1979:6).

The goal of being able to predict patient compliance still eludes researchers. While this model was embraced and used successfully by many researchers, not only in the original application related to preventive health, but also other applications such as aspects of seeking diagnosis and of treatment compliance, it has been unable to provide all the answers (Cummings, Becker & Maile, 1980; Janz & Becker, 1984; Prentice-Dunn & Rogers, 1986). Becker, for instance, expresses this frustration by stating that "... noncompliant patients do not seem to possess any set of manifest characteristics that would enable practitioners to

distinguish them easily from their more adherent peers ..."
(Becker 1979:2).

Cohen (1979) reasons that the research methodology may be at fault, stating "... much of our frustration in finding so few generalisations in the compliance literature stems from a myopic focus on hypothesis-generating models (of research)." Alternatively he favours "... rich, descriptive approaches suited for identifying contextual relationships ..." (1979:XVI).

The subsequent addition to the Health Belief Model of "modifying and enabling factors" and inclusion of a range of factors in "cues to action" point to what Thompson (1984) calls "the sorry truth ... that each bold conceptualisation (of the HBM) flounders on the complicated reality of compliance research and must be elaborated to fit the findings". The HBM "... is still far from being able to predict compliance behaviour." (1984:125). Montgomery et al. (1989) for example found the Health Belief Model less than adequate in predicting behaviour in relation to AIDS prevention, a conclusion reinforced by more recent research.

The HBM focuses on elements of compliance to do with the individual patient. Many studies have successfully used the model to predict compliance but these in the main have concentrated on the "susceptibility", "severity" and "benefit" dimensions of the model. The dimension of perceived "barriers" was only measured in 13 of 29 studies reviewed by Becker (1979:12). In those studies which did measure it, "barriers" were found to be positively associated with compliance in 10 of the 13. Even when "barriers" were measured, investigations were usually limited to factors relating to the organisation's approach to health care. For instance "barriers" to do with, continuity of care, seeing the same practitioner on subsequent visits and so on have been studied.

Such studies do not go beyond the patient-practitioner and clinical setting to any degree and so leave unexplored the wider socio-cultural context of the patient's life apart from the clinic. It is here that other kinds of "barriers" may well

reside. Educators, medical workers and programme planners may be assisted in their efforts to find ways to reduce non-compliance if these are understood.

Compliance studies on leprosy and in Nepal

In the field of leprosy control, patient compliance with treatment regimen is considered vital, both to the patient and to the general public. *Leprosy*, scientifically defined, is a communicable disease, caused by a bacterium (*M.leprae*), curable with antibiotics (used in multi-drug combination MDT). No clear preventive measures are yet known. Leprosy is essentially only controllable through reduction of the pool of infection by treating the existing patients, particularly those with multi-bacillary leprosy, whose disease is understood to be more communicable, thus rendering them non-infectious. *Leprosy control* consequently relies on patients taking adequate prescribed medication. In leprosy control programmes patient clinic attendance is taken as an indirect measure of compliance. This is the measure used for this study.

The most recent critical review of compliance studies on leprosy (Vadher and Lalljee 1992) lists 33 studies carried out between 1974 and 1991. Of these only nine used clinic attendance rates as the measure of compliance. Findings showed unacceptable attendance or non-compliance rates ranging between 9% and 87%. These findings of non-compliance were difficult to compare across studies however as studies differed in their definition or classification of compliance. Of the studies reviewed only three used a cohort design similar to that of this study. Two of these were assessing compliance with Dapsone monotherapy. Their findings were of a range of non-compliance between 71% and 87%. One study (van Asbeck-Raat & Becx-Bleuminck 1986) did look at Multi-Drug Therapy and made compliance measures of urine spot tests as well as clinic attendance. They found clinic attendance rates ranging between 82% and 88% and urine tests at the same time ranged between 84% and 89% compliance which means the non-compliance rates were between 11% and 18%.

Vadher and Lalljee discuss some reasons for a wide variation in findings between studies. One reason for over-estimation of compliance is that many studies do not include those non-compliant patients who had already begun treatment but immediately discontinued, nor those who were detected to have leprosy but failed to keep post-referral appointments. Conversely he suggests that other studies may have understated the compliance problem because of rigorous sample selection requirements preventing the exclusion of some (Vadher and Mansur 1992:606). For example, findings have been recorded of levels of non-compliance with clinic attendance ranging from 30% to 60% from studies carried out in India (Kumar, 1984; Kumar, 1983a, b; Ellard et al. 1988), Tanzania (Hertroijs, 1974), Ethiopia (Low & Pearson, 1974; Ellard 1981; van Asbeck-Raat & Becx-Bleuminck, 1986), Malawi (Ellard et al., 1974), Burma (Hagan et al., 1979), Pakistan (Mull et al., 1989), Nepal (Roche et al., 1989).

Vadher and Lalljee (1992) sum up the evidence concerning the relationship of a number of factors to non-compliance with treatment in leprosy. "...we can conclude that with the exception of one factor - source of referral - the relationships between the variables investigated..." (patient factors of age, gender, education, disease factors of type of leprosy, presence of deformity, organisational factors of distance to travel, miscellaneous factors of season) "... and compliance in leprosy is obscure." (1992:604-5).

While other "miscellaneous factors" such as patient knowledge, features of the regimen, psychological factors, type of clinic, satisfaction with health-care professionals have been investigated he states that findings are "... too few in number to make any meaningful assessment of their contribution to an understanding of compliance in leprosy" (1992:605). Perhaps the findings of this study will shed some more light on this perplexing question.

Clinic attendance: How does this indirect measure of compliance relate to direct measures?

Clinic attendance is taken as an important indirect and practical measure of patient compliance. Having made the choice to use clinic attendance as the measure of compliance applied in this study, it is of interest to ask how the fact of attending clinic may relate to the recent ingestion of the medication itself. Findings in India (Nigam et al. 1979), Ethiopia (Asbeck-Raat & Becx-Bleuminck, 1986) and Nepal (Roche et al, 1989) show that from 9% to 13.3% of clinic attenders may not have taken their medication in the few days prior to attending. Although this is an accurate measure as a spot-test it is not a real indicator of regular, repeated, habitual daily drug-taking.

Just as attendance at clinic may not be exactly equivalent to drug-taking compliance, neither may non-attendance at clinic indicate that the person is not taking medication. While there is no empirical evidence for this statement, findings in this study (from the small follow-up study of ten defaulter patients) showed one who was actually continuing regular treatment from another clinic, and two others who were probably about to resume treatment. They all would have remained "defaulters" as far as the clinic records were concerned. It is recognised, therefore, that attendance at the clinic is an imprecise measure of drug-taking behaviour itself. It is one of the indicators most commonly monitored in leprosy control programmes.

Issues of research design in past leprosy compliance studies.

In their critical review of compliance research in leprosy Vadher and Lalljee (1992) makes concluding remarks of importance to this study and its design. They note that the "... definition and classification of compliance must be clear and replicable ...", that the measure of compliance may be indirect, such as "... appointment-keeping ...", that "A prospective inception-cohort study design is essential to record the extent of non-compliance in leprosy", that factors such as family support, patient health beliefs and attitudes "... are all important in understanding the process of noncompliance", and should "... form a basis for

further enquiry", and finally that investigations should pose questions or relate their findings to "... existing theoretical perspectives." They note that the "... investigations reported ..." in his review "... do not appear to be guided by any theoretical perspective, no *post hoc* attempt was made to relate the findings to existing theoretical perspectives ..." (1992:606).

These issues of compliance study research design are answered in this study which, as mentioned elsewhere, moves beyond the usual indecisive factors to unexplored aspects of the socio-cultural context of compliance including family support and patient beliefs as suggested by Vadher and Lalljee. This study also relates findings to theoretical perspectives. These matters are further discussed in Chapters 4 and 5.

An Indian study identifies factors influencing clinic attendance. Langhorne, Duffus, Berkeley and Jesudasan (1986) found some factors associated with good or poor clinic attendance. Two factors were associated with good attendance: the first was the presence of deformity, and the second was the fact that the patient concerned had presented voluntarily to the clinic for diagnosis and treatment.

Two factors relevant to this study found to be associated with poor clinic attendance were having been found by survey (as against voluntary presentation) and absence from the first or second clinic appointments after detection.

Also of interest are the factors which were found to be not related to clinic attendance. These were socio-demographic and disease-related variables such as age and gender, occupation, clinic size, disease classification, site of skin or nerve lesions, presence of leprosy contacts (family or neighbours known to have leprosy), duration of disease prior to registration and seasonal variation in attendance and travelling distance. Most common reasons given for poor attendance were family and work commitments. This study in Nepal seeks to explore some of the unanswered questions in relation to the area represented by the

"... family and work commitments ..." reasons for poor clinic attendance.

Recent studies of leprosy Nepal

Several theses and other major studies have looked at various aspects of leprosy. Cardinalli (1982) and Pearson (1985) both studied leprosy in Nepal. Cardinalli's ethnographic study of leprosy in Nepal provides useful comparative data for this study with anecdotes and observations about community attitudes to leprosy. Pearson's study looked, from a medical geography and epidemiology point of view, at the social and spacial perspectives of leprosy in Nepal. In relation to compliance, she reported that

...regarding default from and return for treatment, distance apparently played no part. The influences on patients' treatment behaviour were clearly not only spatial, for proximity to treatment centres posed different problems for different patients (Pearson, 1985:360).

Other leprosy studies

In the past two decades a number of major studies of various aspects of leprosy have been undertaken. Some of these have looked at compliance (Pearson, 1985; Sirisook, 1988; Greis, 1988). Others focus on aspects of the psycho-social world of the person with leprosy and on stigma (Flynn, 1972; Gussow & Tracy, 1968, 1977; Volinn, 1983; Wheatley, 1985; Bijleveld, 1976, 1977, 1978, 1980; Waxler, 1981).

Flynn (1972) examined the psycho-social world of the leprosy patient. Gussow & Tracy (1968, 1977) wrote about the patient role of people with leprosy and their regaining their place in society. They identify some patients who deliberately revealed themselves to society as leprosy patients, thus becoming "career patients", and then engaged in educational activities (Gussow and Tracy 1977). It is noted that this use of the term "career" differs from the use in this thesis of the term "sickness or illness career".

Volinn (1983) studies health professionals as stigmatisers and destigmatisers of disease, taking alcoholism and leprosy as case studies. Wheatley (1985) wrote about leprosy, a disease apart, and analysed stigma historically and cross-culturally. Bijleveld (1976, 1977, 1978, 1980) studied and reported on leprosy in Kenya focussing on community, leprosy patients and expectations, experiences and stigma. Waxler (1981) focusses on the person with leprosy learning to be a leper, a case study of the social construct of illness. Sirisook (1988) studied compliance among leprosy patients in urban Thailand using theories such as the HBM as well as perceived self-efficacy, and suggests that they only account for 25% to less than 40% of the variation found in compliance behaviour. She suggests inter-disciplinary approaches be taken and that the role of the family be studied in relation to compliance in leprosy. Greis (1988) wrote on compliance and stigma, with fear of being known as a leprosy case a feature of his work (German).

Five Asian studies use some concepts chosen for this study.

The concepts used in this study such as explanatory models, differentiation between illness and disease and the broader cultural context have been elements of the frameworks for studies in Thailand (Neylan et al., 1988), Indonesia (Elissen and Hamme, 1989), Pakistan (Mull et al., 1989) and India (Weiss, 1990; Aagaard-Hansen, 1991).

1. Neylan et al. (1988) found through open-ended questionnaire interviews that patients held a wide range of etiological theories. The bacteriological cause of leprosy was mentioned by very few of the interviewees.

2. Elissen and Hamme (1989) obtained their data from open-ended personal interviews with patients and subsequent discussions with a small group of patients. They found that only 7% of their sample mentioned the bacteriological origin of leprosy. They found that "although most patients did not feel any discrimination on the side of the community, there is a wide-spread sense of personal shame among themselves ..." (1989:19). This was exemplified for them in that some of the interviews

conducted in the homes of the patients had to be done at night and in subdued voices "out of anxiety that neighbours would come to know about their disease" (1989:19). They also recommended that "besides the modern medical theory, cultural beliefs and religious views have to be taken into consideration ..." (1989:20) in health education based on a multi-disciplinary approach .

3. Mull et al. (1989) interviewed leprosy patients in Pakistan. They found a similarly small proportion (4%) of patients attributing the disease to infectious organisms. They found that leprosy in Pakistan among the people studied was associated with severe stigma and that the presence of such a dread diagnosis in the close-knit extended families of that area could "... spell the end of job and marriage prospects for even distant relatives ...". They suggest that the "... term "non-compliance" appeared to be an oversimplification since it covered so many different types of culturally constrained behaviour". This study provides an example of how socio-cultural insights aid the understanding of how complex is compliant and non-compliant patient behaviour.

4. Weiss (1990) explored patient experiences of leprosy in India and writes of the emotional burden of leprosy. His work is discussed in Chapter 11.

5. In his study of leprosy in its cultural context in South India, Aagaard-Hansen (1991) contrasts the biomedical and traditional notions of leprosy (Lepra and Kustam/Tempal). He develops a trans-cultural model of communication.

An example study of compliance using anthropological methods

In their study of epilepsy patients, Trostle et al. (1983) explored the management of epilepsy from the patient's point of view. They concluded that from the patient's viewpoint biomedical strategies form one facet of many coping mechanisms in the management of epilepsy. They found that "... the gulf looms large between the physician's treatment of the *disease*, and the patient's management of the *illness*". They stressed in their conclusions that "... non-compliance from the patient's point of

view is often rational, understandable, and justifiable, given that social forces unrelated to a biomedical model influence his or her behaviour." (1983:35). From this study it is evident that use of anthropological methods and concepts such as the differentiation between illness and disease held potential for uncovering useful, new insights into compliance, the subject of this research.

Compliance in general

Various reviews of compliance literature (Davis, 1966; Blackwell, 1973; Ley et al., 1976; Sackett & Haynes, 1976; Cohen, 1982; Evans and Spelman, 1983) have found that the *extent of non-compliance* with medical advice/regimen ranges from 15% to 93% and averages somewhere around 45% to 50%. Non-compliance with a long-term *prophylactic* regimen has been found to be 66% after three years (Gordis, 1969) while non-compliance with a long-term *curative* regimen is between 32% and 59%. For instance, anti-TB programmes experience 30% to 72% non-compliance rates (Davis, 1966; Hertroijs, 1974; Schwartz et al., 1962).

Evans and Spelman (1983) conclude that in general "... non-compliance with drug treatment is widespread ...", there is "... general agreement that when patients are given medication by a doctor, nearly half will either not take the drug or not take it as prescribed ..." and "... most will stop treatment as soon as they feel better". They go so far as to say the phenomenon is so widespread that it might be considered normal behaviour. The same authors also assert: "Most of the factors which influence compliance and non-compliance are to some extent *controllable by the doctor and not by the patient.*"

While doctors tend to blame individual patient characteristics for non-compliance, few social and demographic factors have been shown to correlate with compliance and non-compliance (Becker 1979:5). Heszen-Klemens (1987) studied how doctors manage their patients' non-compliance. She found that

...non-compliance is a source of doctors' frustration and is perceived as an ego-threatening event by the majority of

them. As a consequence, doctors' activity is aimed first of all at ego-defence, while the original goal of behaviour, i.e. the management of non-compliance, is neglected.

When health professionals, who in their own society hold these opinions, move into a cross-cultural setting, the likelihood of failed patient education efforts may be amplified through the use of a "cause and effect" model of health education (discussed below), together with ego and ethno-centric approaches to the problem. The ethnomedical approach and application of the model of health education in the cross-cultural setting of Nepal provide new insights into the problem of compliance in leprosy control in Nepal.

A statement by Cohen (1979) in his summing up of new directions for patient compliance provides reinforcement to the decision made regarding the scope, focus and methods used in this study. He said:

Just as understanding a word or event is context-dependent, the discovery of laws of human behaviour in general, and patient compliance in particular, will require understanding contextual constraints. (1979:160-161)

In his 1982 discussion of issues in patient compliance, Davidson identifies not one but four or five generally mutually exclusive literatures on compliance, thus illustrating the complex and debated nature of compliance (1982:417). He suggests that medical compliance literature sees compliance or non-compliance as a personal trait of the patient or a feature of the practitioner or situation. He questions the implicit assumption in reports of compliance in the medical literature that compliance is a phenomenon which occurs, somewhat like an infectious disease, for which we need to find a proper prescription for its cure (Davidson 1982:421).

He goes on to discuss social compliance with theories of social exchange, social influence, forced compliance and ideas of self-efficacy and focus of control important to the understanding of compliance.

He then looks at behavioural compliance with self-reinforcement, self-monitoring, behavioural contracting and self-instructional training as helpful for improving compliance. He finishes by pointing to two paradoxes, one being too much compliance and the other the difficulty of understanding why people seem to make informed choices which at times result in deterioration in their physical condition.

He points out that the search for factors related to compliance has yielded a long list of what compliance is *not* related to. These are patient characteristics such as age, sex, race, religion, education, socio-economic status, types of illness, onset of illness, attitudes to the doctor, and personality measures. Factors of the situation such as doctor-patient interaction, type of agency attended, family interaction of the patient, and distance to the site of treatment have similarly been shown to *not* be closely related to compliance.

What Davidson does is point out the difficulty of finding a satisfactory definition and explanation for compliance and non-compliance, and in particular he hints that the traditional concentration of factors commonly found in studies in medical compliance, related to patient, practitioner and situation do not hold the key to further understanding compliance. It is with this in mind that the present study moves beyond these three traditional elements to focus on the cultural context of compliance in Nepal.

The studies mentioned above have shed some light on factors associated with the patient, the practitioner-patient relationship and clinical setting, which are and are not associated with compliance and non-compliance. Non-compliance is widespread and common (32-59%), frustrates health professionals, is associated with factors which may not be controllable by the patient, and the list of factors found not to be associated is long. There are few findings which relate to the cultural constraints operating in the lives of people with leprosy.

The suggestion of Cohen (1979) that discovery of laws of human behaviour related to compliance requires an understanding of contextual constraints, and the remarks of Mull et al. (1989) that compliance and non-compliance cover so many types of culturally constrained behaviour best sum up the approach to this study of patient compliance in Nepal. People with leprosy in Nepal make their decisions in their social and cultural context and the health professional seeks to understand the constraints with which they contend and to adjust programmes accordingly.

It is therefore clear that the decision to study leprosy compliance in Nepal in the socio-cultural context of the patient held potential for uncovering previously unexposed associations particular to leprosy and Nepal, but with general application in similar cross-cultural settings and cultures and with similarly stigmatizing conditions.

Medical systems and world view

Foster and Anderson (1978) suggest that there are three main types of medical systems. The *personalistic system* believes that illness results from supernatural ... non-human ... or human ... aggression or punishment directed specifically against ..." the person (1978:53).

Naturalistic systems explain illness "... in impersonal, systemic terms ... conform(ing) to an equilibrium model ..." That is "... when ... equilibrium is disturbed, illness results" (1978:53).

Neither of these systems, as Foster and Anderson note, is adequate for explaining contagion: "... only with the development of the scientific concept of pathogens can the transmission of disease from one person to another be easily explained" (1978:67). They assert that "in a complete classification of worldwide medical systems, "*scientific*" or "*Western*" ... medicine would constitute a third type" (1978:79).

These types of medical systems assume a cultural defining of illness; its causation, and its diagnosis as disease; with curers

who use diagnosing, curing, managing and preventing strategies flowing logically out of theories of causation. *Belief about causality* is therefore the logical starting point for description of major aspects of medical systems: "... if we give a clear description of what people believe to be the cause of illness, we can in broad outline fill in the other elements in that medical system." (Foster & Anderson 1978:67). An outline derived from Foster and Anderson is used as a basis for description of Nepal's medical systems.

In Nepal: A variety of beliefs and practices related to health

The colourful cultural and religious mosaic formed by Nepal's peoples is reflected in the variety of their beliefs and practices relating to health and illness. Medical anthropology provides the above framework which is useful for describing and understanding the ethnomedicine of Nepal, *ethnomedicine* being "... the ways human groups handle disease and illness in the light of their cultural perspective", and "the study of how medical problems are realised and dealt with in different societies" (Fabrega 1990:201).

Various researchers have written of the complex medical system, practices and adaption to new ideas in Nepal, for instance Stone (1976), Blustain (1976), Miller (1979), Shrestha and Lediard (1980). As their writing provides the essential, specific context to this cross-cultural examination of compliance behaviour in Nepal, a full review is presented separately in Chapter 7.

Various groups in a society, in the realisation and dealing with their illness problems, develop and use their own medical systems and medicine. A useful definition of a *medical system* is given by Landy :

A society's *medical system* is the total organization of its social structures, technologies, and personnel that enable it to practise and maintain its medicine (*as defined below*), and to change its medicine in response to varying intra-cultural and extra-cultural challenges.

A society's *medicine* consists of those cultural practices, methods, technologies and substances, embedded in a matrix of

values, traditions, beliefs and patterns of ecological adaption that provide the means for maintaining health and preventing or ameliorating disease and injury in its members (1977:131).

Fabriga sees ethnomedical study involving the interplay of disease, illness, medicine and culture (1977; 1990).

Development of medical taxonomies

Medical taxonomies differ from society to society. Different societies develop differing ways of defining and dealing with illness episodes. These ways of dealing with biological and behavioural differences involve semantics (symbolism and meaning attached to the particular episode) and the way it is defined determines how it is dealt with both by the individual and by the society in question. Fabrega (1977) claims that:

The accumulated experience which groups have with illness and with its treatment yields a formal body of knowledge which is more or less codified in the group as their (medical) theory of illness. This is an outgrowth of the process of group adaption and cultural evolution. (1977:203)

Thus group members are provided with explanations of why illness occurs and with processes for dealing with them. The names a group uses for illness and its knowledge relating to them is termed its *medical taxonomy*. This medical taxonomy, along with other aspects of medical systems, is seen as developing and changing in the context of broader socio-cultural and political changes in the society or group. Medical taxonomies contain both folk and formal definitions. Distinctions made by a society between illness and non-illness as deviation from normal are also subject to change and development.

World View

In the culture of any people there is said to exist a "... shared framework of ideas ... concerning how they perceive the world" (Burnett, 1990:13). It is the framework upon which that people perceives reality. The medical system of a culture is part of this reality. The world view of any people is one of the givens: it is not explicit but may be implied from words and actions. Kearney defines world view as:

... a people's way of looking at reality. It consists of basic assumptions and images that provide a more or less coherent, though not necessarily accurate, way of thinking about the world. A world view comprises images of "Self" and all that is recognised as "not-Self", plus ideas about relationships between them... (1984:41)

Hiebert (1983:356) puts it this way, "Behind the observable patterns of human cultures seem to lie certain assumptions about the way the world is put together". These assumptions deal first of all with overall reality, with the universe and the meaning of life. On another level are a system of values and beliefs, behavioural norms and differentiation between right and wrong.

Some of the functions served by a culture's world view assumptions are of particular relevance in the crafting of this thesis. First is the cognitive foundation they provide for building a system of explanations providing sense to beliefs. Second is the emotional security provided in the face of a dangerous world of unpredictable and uncontrollable crises. "It is not surprising, therefore, that world view assumptions are most evident at ... rituals people use to recognise and renew order in life and nature". (Heibert, 1985:48)

Two world views, namely the western scientific and the traditional Nepali, provide the essential foundation for descriptions and explanations of the phenomena observed in this study.

Health, medical practice and World View

In 1977 Engel appealed to western medical practitioners to broaden their focus in practising scientific medicine. He suggested shifting from an almost exclusive concentration on the biological/bodily aspects of health and illness by embracing the psychological and social aspects as well. In summary he states that for the West "the dominant model of disease today is biomedical, it leaves no room in its framework for the social, psychological, and behavioural aspects of illness". He proposed a bio-psycho-social model as a basis for research, teaching and real life action (Engel, 1977). The addition of culture to

Engel's bio-psycho-social model rounds off the search for a definition of health for this study.

If health is thought to relate to physical or biological well-being only, then medical practitioners, health care programmes and institutions need only concern themselves with these matters. If the World Health Organisation is correct in also including "mental and social well-being" in its definition of health, then health professionals and programmes need to include psychology, psychiatry and social welfare as well in their programmes.

To define health and illness as medical anthropologists do in the broad cultural context - more specifically in the context of the prevailing medical systems in a cross-cultural situation - enables approaches to health education and structuring of health care delivery systems to be informed by and adapted to that culture. For the study of health education in a cross-cultural setting like Nepal and dealing with a phenomenon like leprosy, it is fundamental to embrace a comprehensive definition of health in the context of that culture.

The definition of health in this study fulfills these criteria. It conceives of health cross-culturally as *a vital, dynamic harmony between the elements which make up human beings living in their environment*: where *vital and dynamic* imply responding, coping, adapting, learning, growing and adjusting; *harmony* means balance or equilibrium; *humans* are physiological, physical, psychological, intellectual, spiritual and social beings. *Their environment* includes the *intrinsic environment* inherited and accidental capacities or limitation, the *physical environment* of biological, chemical, climatic and geographic surroundings, as well as *social environment* of relatedness and belonging to groups, associations and organizations and *cultural environment* or network of beliefs, values, practices and ceremonies held in common with others of that culture.

Health in cultural context

Many writers, such as Mechanic (1962, 1968), Zola (1966, 1977, 1981), Foster (1965, 1982), Foster and Anderson (1978), Kleinman (1980, 1988) and Kleinman and Eisenberg (1978) place the individual and his health not only in his social, but also in his cultural context. Paul (1955:477) put it this way: "The threads of health and illness are woven into the socio-cultural fabric and assume full significance only when perceived as part of the total design." And Knutson (1965:47) states that "to consider the health status of any individual or group ... requires an understanding of ... broader socio-cultural variables ..." such as "nationality, religion, caste, class ..." which "... directly affect the health status of individuals who share them."

The prospect of having to study an entire culture in order to understand the health status of an individual would be very daunting. While recognising that culture is always integrated, there is one aspect or system of a culture which, if understood, may assist with a clearer understanding of patterns of health and illness in that culture.

Kleinman (1980:24, 45-70) suggests that health care systems integrate health-related components of society and are provided with much of their specific content by their cultural setting; cultural rules and meanings shape health care systems. The socio-cultural adaptive strategies employed by human beings "... bring into being medical systems, the culturally based behavior and belief forms that arise in response to the threats posed by disease" (Foster & Anderson, 1978:33). This concept of medical systems provides part of the basic theoretical framework for the study.

Medical systems are dynamic.

Changes in a group's medical taxonomy also take place when they are brought into contact with groups with other medical taxonomies, such as can be seen taking place in Nepal. Ethnomedicine is therefore the study of how human groups handle disease and illness, and of the medical institutions, personnel and procedures they develop in the light of their cultural

perspective. However, ethnomedicine is also concerned with *"how definitions of illness change across time in a particular group and with the related changes in medical care practices and approaches to non-illness."* Changes that take place through exposure of one medical system to another are also in the realm of ethnomedicine. Medical systems of groups change across time, within and between groups (Fabrega, 1977). Historical development and adoption of ideas, explanations and practices emerge from the past experiences of groups of people. Explanations of illness are part of these.

What is categorised as Illness and Non-illness?

In any culture, explanations of illness carry with them expected practices relating to remedy and management. Groups in society explain the behaviour of others in their own way. Social groups differ in their ways of making distinctions between behaviours. If behaviour is thought of as either adaptive or mal-adaptive a continuum can be pictured. At one end of such a continuum of adaptive/non-adaptive behaviours, individual behaviours can be categorised positively as "normal", while at the other end they can be seen negatively. Behaviour deviations at the negative pole of such a continuum may be divided into *illness* and *non-illness*. Both of these embrace what are seen as deviations from normal. The group and the individual concerned "view illness as requiring help or corrective action" (Fabrega, 1977). Non-illness, on the other hand, may be handled in a more punitive fashion, having been defined as bad, even criminal.

Such distinctions between types of deviations from normal (i.e. illness and non-illness) are also subject to change and development. For example, in our western society such a shift has occurred or is occurring for conditions like alcoholism, homosexuality and HIV infection. Are they illness or non-illness? The answer to this question determines the options chosen for dealing with them. These concepts are useful when considering leprosy as explained in Nepal.

Explanations of why and how and what illness is and how it may be eliminated are thus provided for different groups. This *medical*

taxonomy (naming of illness, disease, sickness) along with other aspects of medical systems, is also seen as developing and changing in the context of broader socio-cultural and political changes in the society or group. In other words definitions of illness and disease, phenomena understood to be sickness, may become the subject of debate and are not fixed. Changes in a group's medical taxonomy also take place when they are brought into contact with groups with other medical taxonomies. Medical systems of groups change across time, within and between groups. Such change can be seen taking place in Nepal. In particular, the health education of the NLCP has attempted to bring changes to the various explanations of leprosy made by different groups in Nepal.

Distinctions between illness, disease and sickness

It is important at the outset to distinguish clearly between illness, disease and sickness. The terms "sickness", "disease" and "illness" are used interchangeably in everyday language, but for the purpose of making distinctions between different dimensions of people's experiences they are given specific meanings. Twaddle and Hessler (1977) set out the distinction by placing these terms in the context of the sociological labelling theory. "How people behave toward another .. depends to a great extent on who they think that person is. Who they think a person is ... depends on how..." they have been labelled. They explain it this way:

Whereas disease is a socio-*biological* status and illness is a socio-*psychological* status, sickness is a *social* status. The events that lead to the definition of sickness may be either disease or illness or functioning in the social order. Furthermore, whereas the investigation of disease is the province of biology and medicine and that of illness is the province of psychology, sickness is the unique province of sociology. (1977:96, 97)

Kleinman and Eisenberg (1978) add the cultural dimension to the distinction between disease and illness.

...disease in the western medical paradigm is mal-functioning or mal-adaption of biologic and psychophysiologic processes in the individual, whereas illness represents personal, interpersonal and cultural reactions to disease or discomfort. (1978:252)

Illness and disease are said to be "... separate aspects of a complex, fluid, *total phenomenon: sickness*". In 1980 Kleinman differed from Twaddle and Hessler by stating that disease and illness are two aspects of sickness (Kleinman, 1980:72). Illness can be said to be culturally constructed because the illness experience is strongly influenced by culture, being "... part of social systems of meaning and rules for behavior ...". The ways illness is experienced and coped with flow out of the culturally-shaped explanations of sickness employed by the individual and his society. The authors state:

For patients, *illness* problems - the difficulties in living resulting from sickness - are usually viewed as constituting the entire disorder. Conversely, doctors [in the biomedical system] often disregard illness problems because they look upon the *disease* as the disorder. Both views are insufficient. Medical anthropologic studies show that traditional healing in developing societies and popular health care in our own are primarily concerned with *illness* ... with treating *the human experience of sickness*. On the other hand biomedicine is primarily interested in the recognition and treatment of *disease* (curing). ... Biomedicine has increasingly banished the illness experience as a legitimate object of clinical concern. ... This systematic inattention to illness is in part responsible for patient non-compliance...

Again, Eisenberg and Kleinman (1981:13) make the distinction thus: "physicians diagnose and treat disease ... patients suffer illnesses". In 1988 Kleinman terms *illness* as the "human experience of symptoms and suffering,..." how sick people and their wider social network "... perceive, live with and respond to symptoms and disability". "*Disease* is the problem from the practitioner's perspective." However the term *sickness* is given more depth and is now defined as: "... the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces". For example, to talk about the relationship of tuberculosis to poverty is to speak of "tuberculosis as sickness" (Kleinman, 1988:3-6).

Robinson (1990) used these distinctions recently in analysis of patients' personal narratives. *Illness* is a self perception, *Sickness* is a social perception and *Disease* is a biomedical perception.

These distinctions made by Robinson are more succinct than those given above and will be used for the purposes of this study; that is, as they apply in a cross-cultural setting, disease as a *biomedical perception* is taken to mean *bodily changes* and the process of labelling conditions as disease to be by *specialists* or curers from within the group concerned, not just by biomedically orientated physicians; thus the disease concept is broadened to allow for the setting of the study, a cross-cultural scene with a plurality of medical systems.

In the ethnomedical approach taken in this study the definition of illness is the subjective experiences of the patients, an experience shaped by the social and cultural setting in which they live, their ethnomedical system. Disease likewise is taken to be the biological changes as detected and given a label "disease" by expert practitioners in and according to the particular medical system setting. Sickness is the problem as perceived and named by the society concerned and certain changes to social roles and intercourse may be expected accordingly.

Explanatory models and sickness (illness) careers

The concept of "sickness career" provides a general framework against which to present the experiences and series of decisions made by people with leprosy in Nepal. It is noted that the idea of explanatory models (Kleinman, 1988) follows to a limited extent the general pattern of the sickness career. In this thesis it serves as a framework useful for understanding elements of patient compliance behaviour in particular. Twaddle & Hessler (1977), in discussing sickness career state that "sickness ... implies changes in social identity and expectations for behaviour" (1977:122). They go on to say:

To understand the sickness, and complexity of human behaviour in response to symptoms requires that one look at the social processes that influence behaviour. These include an active process of decision making that leads to a series of discrete identities and expectations constituting a career.

They suggest that changes in identity which attend disease or illness are the focus of the "sickness career" (1977:123). Roth (1963) applied the concept of career to life events other than occupations. A career according to him is "... something a person goes through over a period of time and has definable stages or signposts and more or less definite end points ..." (1963:94,95).

While being common in medical sociology literature, the concept "sickness career" has rarely been applied in leprosy (Waxler, 1981; Gussow and Tracy 1968). Others have examined the stages or changes in status and different roles adopted in the process of people passing from wellness to illness and beyond (Roth, 1963; Twaddle and Hessler, 1977; Safillios-Rothschild, 1970).

In this thesis the sickness career framework takes in the transition from "health" or a general state of well-being to "illness", when a problem is noticed for which help is sought, and further, to "disease", when the problem is named and treated by a practitioner, and on to various end points such as "cure", noting whether there is restoration of physical, psychological and social aspects of health or "sickness", meaning social labelling as a leprosy sufferer.

Illness Career

In the application of the concept of sickness career to leprosy in Nepal, it is called "illness career" because for the most part it deals with the experience of people with leprosy who personally perceive themselves to be "ill" but are not socially labelled as "sick" or lepers (KUSTAROGI in Nepali).

Explanatory Models

In this thesis aspects of the explanatory models of several categories of people with leprosy are described and form part of the models of "illness careers" presented in Chapter 11. Explanatory models provide a framework for eliciting, describing and comparing the understanding of an episode of illness of various players in the health care system. Explanatory models of illness form part of the medical world view of these people.

Kleinman suggests that "explanatory models (EMs) are the *notions about an episode of sickness* and its treatment that are *employed* by all those engaged in the clinical process" (1980:105). For any particular episode of sickness, five main questions are set out to which answers are sought in EMs:

- (1) etiology;
- (2) time and mode of onset of symptoms;
- (3) pathophysiology;
- (4) course of sickness; and
- (5) treatment.

Explanatory models draw on but are *distinct from the general beliefs about sickness and health care*, the *health ideology* of the people concerned, as they relate to dealing with a particular episode of sickness. The following are the topics included in the EM framework in order to be able to *construct patient illness careers* from interview data.

- (1) The problem, how recognized, by whom, how defined.
- (2) Help seeking.
- (3) Impact of the diagnosis of leprosy.
- (4) Perception of community expectations of leprosy patients.
- (5) Family history and situation.
- (6) Cost of attending clinic.
- (7) Stigmatisation.
- (8) Role changes.

These two lists were combined by the author to form an *Interview Guide* and *Check List* within the research study.

Social integration

When studying a subject like leprosy, which is known world-wide as a stigmatised condition (Bijleveld, 1978; Waxler, 1981; Volinn, 1983; Wheatley, 1985; Greis, 1988; Mull et al., 1989; Elissen & Hamme 1989), consideration of the social status of patients, their place in their families and communities are of special interest. Do patients retain their places and usual roles in their social settings? Or are their status and roles disrupted as a result of their problem? These are questions which are asked.

In Nepali culture the concept of social integration or separation has to do with two aspects of practice. The first relates to the Hindu notions of ritual purity and impurity. These notions were formalised in legal terms in the Legal Code of Nepal between 1854 and 1963 in laws related to relationships between castes (Macdonald, 1984:283 ff.; Bista, 1991:58). The second relates generally to Nepali community life, to what Bista calls AFNO MANCHHE (1991:98), a term used to designate one's inner circle of associates. People who are outside one's inner circle are non-persons. It also relates to aspects of family and village life, to what Miller calls IJJAT, prestige or reputation, and family-centred and caste-centred DHARMA or morality (Miller, 1990:123ff).

As Mull et al. (1989) found in Pakistan, Nepali leprosy patients have reported similar dread of losing family status and prospects for future welfare, such as finding suitable marriage partners for children. In this study particular attention is paid to whether patients remain with their families and whether their families remain in their village or have moved since the diagnosis of leprosy was made.

Accommodation

Of particular relevance to this study is the notion that world view monitors cultural change, helping in the reinterpretation of existing ideas in the process of confronting new ideas so that they fit the overall cultural pattern. Burnett speaks of the Hindu world view, the predominant but not the sole philosophy of Nepal, as having an "... amazing plasticity which allows it to adapt to new situations, and yet remain true to its ancient assumptions". He sees it as having an "... ability to synthesise, and allow individual variety and creativity ..." (Burnett, 1990:87). In this study these abilities are seen reflected in what to western minds seem like ambiguities of belief.

Bista (1991) speaks of the blending or integration of new practices into long established systems of belief in Nepal, with

the people tolerating the incoming new system "... as long as it did not try to contradict their own religious faith and practice" (1991:32). He speaks of some ethnic groups in Nepal however being

... more singular in their worship, which tends to be predominantly Shamanistic with few inroads by these other belief systems. ... the Tibetan-speaking peoples of the high Himalayas are an exception as they have integrated Buddhism with their Shamanis practices (1991:33).

It is this kind of accommodation of new ideas which is seen to add new western medical concepts and cures to those already existing that is of special interest to the health educator in this study of leprosy in Nepal.

Health education

For this study health education means to design and carry out health education interventions aimed at having people make changes and take actions conducive to their health. Implicit in this definition is the notion that the individual or community has the ability to do things differently, and that through doing things differently, can bring about improvement to their health. It implies that after learning, the individual or group makes a choice, a voluntary decision to change. This definition of health education came from the PRECEDE model.

The PRECEDE model was published in Green et al. (1980). In their introduction the authors suggest that health professionals "... have an understandable tendency to begin with inputs" when faced with a health behaviour problem. Because they are orientated to take action, health professionals, after quickly glancing at the problem, "... immediately begin to design and implement health education interventions and assume that the outcome will occur automatically". However the assumption that "education" (inputs) will automatically yield "health" (outcome) is flawed. This simple "cause and effect" or behaviourist stimulus/response model for explaining human behaviour provides a rudimentary but inadequate framework upon which to base health education planning. The *PRECEDE Model of Health Education* begins at the

other end. It "... begins with the *final (desired) outcome* and asks *what must precede that outcome by determining what causes that outcome.*" (Green et al. 1980:12)

In determining what must precede the desired outcome, the PRECEDE model moves through several major *phases of diagnosis of the problem*; namely, Social and Epidemiological, Behavioural, Educational and Administrative Diagnosis. The seven basic phases of this model are:

Phase 1. Consideration of the "quality of life" assesses some of the general problems of concern to the people in the population of patients, or whoever. The kinds of social problems a community experiences are a barometer of their quality of life.

Phase 2. Identifies specific health problems that appear to be contributing to the social problems. These are then ranked and a selection made of those deserving allocation of resources.

Phase 3. Particular health-related behaviour that appears to be linked with the chosen problems is identified. Non-health behaviours are beyond the scope of the Health Educator.

Phase 4. Three classes of factors potentially affect health behaviour, namely, predisposing factors, enabling factors, and reinforcing factors. Factors likely to have direct impact on the behaviour selected in Phase 2 are categorized accordingly.

Phase 5. Asks which of the factors thus categorised are to be the focus of the educational interventions.

Phase 6. The intervention programme is developed and implemented along with an assessment of administrative problems and resources.

Phase 7. Evaluation is of necessity an integral and continuous part of working with the whole framework (Green et al. 1980:12-16)

Health education becomes health promotion

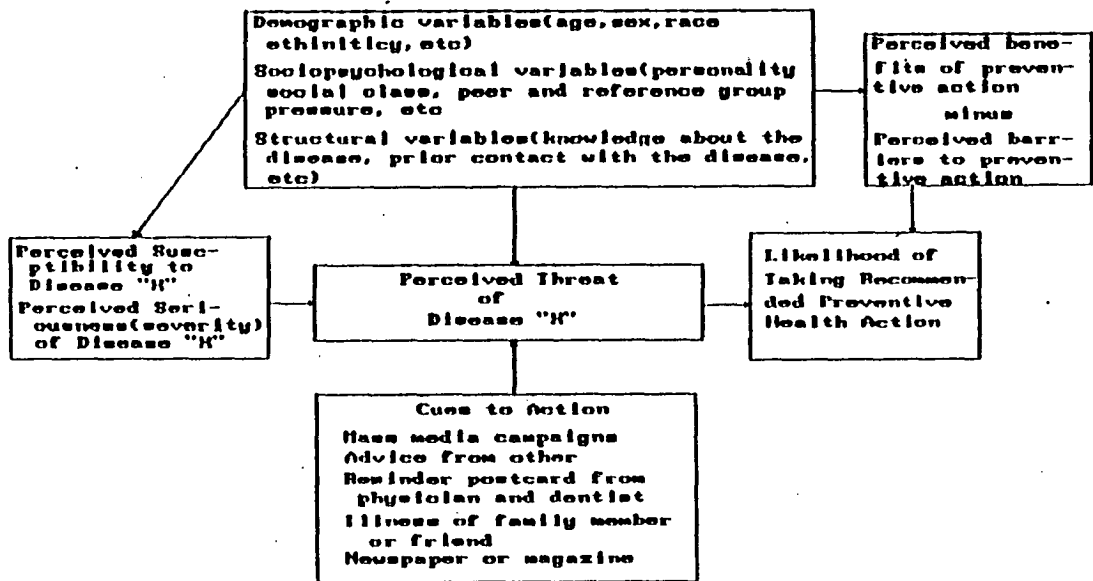
Green & Kreuter, in considering progress in health education during the twelve years since PRECEDE, added other dimensions to the model. A systematic presentation of the emergence of **health promotion** over that time is to be found in the second edition first chapter. It was clear that individuals and communities did not control all the factors affecting their health. It was logical that health education interventions which focussed only on *individual* or community behaviour-change would be only partly effective in a quest for health. The addition of efforts to change *systems* therefore followed. PROCEED has been added to PRECEDE. Their introduction states:

... we have expanded the (PRECEDE) model to accommodate the more comprehensive field of health promotion. Thus the diagnostic approach now **encompasses the social forces** that influence lifestyle and health, as well as the more specific behavioural influences on health and the more immediate educational influences on behaviour. (Green & Kreuter, 1991:XIX)

The purpose of the new PROCEED dimension is to move "... beyond educational interventions ..." by bringing into play "... political, managerial and economic actions necessary to make social systems and environments more conducive to healthy lifestyles ..." (Green & Kreuter 1991:XX)

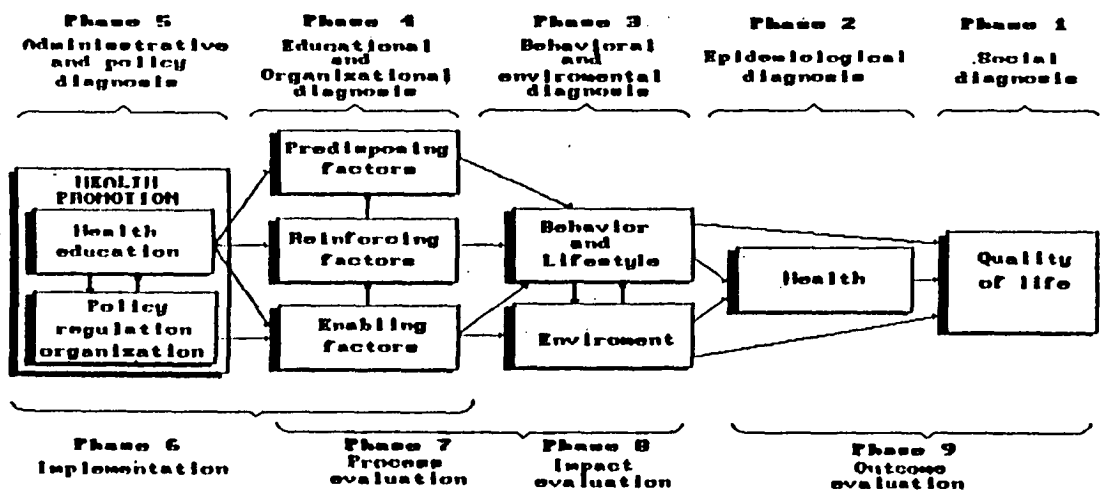
Health promotion is defined as "... the combination of educational and environmental supports for action and conditions of living conducive to health". Combination "...refers to the necessity of matching the multiple determinants of health with multiple interventions or sources of support." *Educational* "... refers to health education as defined..."(above). *Environmental* "... refers to the social, political, economic, organisational, policy, and regulatory circumstances bearing on the behaviour or more directly on the health." *Living conditions* "... ranges ... beyond the strictly behavioural into the more complex web of culture, norms, and socio-economic environment ... of lifestyle." In relation to this latter point, the authors state that this complex web "... is the least well-defined or researched aspect of health promotion..." (Green & Kreuter, 1991:17) Figure 2:2.

Figure 2:1



The "Health Belief Model" as predictor of preventive health behavior (Becker 1974)

Figure 2:2



(Green and Kreuter, 1991: 24)
The PRECEDE-PROCEED model for health promotion planning and evaluation

In this thesis the examination of leprosy in Nepal ventures into and researches the *more complex web of the culture and norms* of people with leprosy. This investigation carried out in this cross-cultural setting, using a comprehensive definition of health in the context of that culture, illustrates the strengths and limitations of the global models, the Health Belief Model and the PRECEDE/PROCEED Model, for understanding and solving health related problems unless they are augmented by culture and setting specific investigation carried out using an ethnomedical approach.

This thesis describes the variety of Nepal's ethnomedicine with its complex combination of systems in Chapter 7. This forms the context in which the NLCP was established and health education undertaken in the 1970s and 1980s. Beliefs about the origins of illness are taken to indicate basic ways of understanding illness held by the Nepali people who were and are the "target" of health education in the NLCP.

Cross-cultural confrontation

Kleinman (1980) comments that the western health professionals, because of their professional socialisation, tend to consider their own ideas about health and illness rational while those of patients, lay public, folk practitioners appear to be irrational and "unscientific". When health professionals with a scientific approach, which they regard as "rational", move into a cross-cultural setting, their efforts at patient health education are more likely to fail because, not only do they adopt a "cause and effect" model of health education, but they also adopt an ego- and ethnocentric approach to the problem. This results in them confronting and excluding traditional medical systems from their beliefs about proper medical practice.

Ethnomedicine, health education and leprosy control

Anthropologists can shed light on the dynamics of case-holding as compliance in relation to health education and leprosy control. According to Foster (1984), specific diseases like leprosy "...

lend themselves to anthropological study". Problems such as "... case-holding in ... tuberculosis and leprosy control programmes would ... benefit from anthropological input". He says:

I believe anthropological research can play an important role in improving health education assumptions and practices. Our knowledge of ethnomedicine is critical to this role; we must demonstrate to health educators exactly how a knowledge of prevailing health beliefs and practices must be the starting point in planning health education campaigns ... To be fully effective communication skills must be coupled with ethnomedical information. (Foster, 1984:852)

Health education aims to bring change: Who should change?

Foster (1982, 1984, 1987) discusses the problem that while "... at least half of the problems encountered in providing health care to traditional peoples are bureaucratic in nature" and that administrators assume that "... if changed behaviour is essential to improved health levels, it must be the individual and community, not bureaucratic behavior that changes".

As noted above, health education has to do with changes in health-related behaviour in individuals and groups at risk. However, health promotion does not stop there: it considers changes in organisational, administrative and legislative structures and provisions to be legitimate targets for its programmes. Consequently a health education and health promotion programme which only aims to change individual patient behaviour could be considered to be incomplete. The findings of this study provide an example to back up this claim.

A broad ethnomedical approach is taken in this study because it is recognised that past approaches to health education in the LCP have been based on the limited biomedical model and have had limited success in reducing the compliance problem. In Nepal, as elsewhere, this limited approach has taken little or no account of "illness experience", concentrating instead on "disease" as defined by biomedicine. The ethnomedical approach taken in this study deals with a medico-behavioural phenomenon in terms of the personal and cultural context in which it is found. It seeks the associated symbolic system, the meanings, the interpretations

placed upon the "illness", "sickness" and "disease", and the methods of dealing with leprosy in the culture and medical systems of Nepal.

In the initial cohort study of compliance, the thesis uses epidemiology as its initial basis for defining leprosy and the Leprosy Control Programme, but consciously moves to an ethnomedical position for clarifying the perspective of the public and patients of Nepal and for gaining further understanding of the processes of compliance and non-compliance.

All the concepts mentioned above are necessary to the picture composed as a result of this study of leprosy in its cultural context in Nepal. The next chapter (3) gives the background to the study and Chapters 4 and 5 discuss the research approach, methods and implementation and analysis of the research data which were gathered in Nepal from January to November 1990 and October 1991 to February 1992.

CHAPTER 3 : BACKGROUND TO THE STUDY

The National Leprosy Control Programme (NLCP) of Nepal was established in 1974 with assistance from the World Health Organisation (WHO) and through agreements between His Majesty's Government of Nepal (HMG/N) and various non-government organizations (NGOs). HMG/N assigned to the International Nepal Fellowship (INF), a Christian NGO, responsibility for funding, establishing and managing the (NLCP) in the then Western and Far West Regions of Nepal. As a result, between 1974 and the mid-1980s, the first-ever leprosy services were established systematically district by district in the western half of Nepal.

In 1980 the NLCP in western Nepal reviewed the experience of the first five years and decided to change its strategy for case-finding and case-holding. The new strategy, to be applied in the ongoing expansion of the leprosy services to new areas of Nepal, contained two equally important elements. One was to establish and maintain quality care, in recognition that any new patients found needed to be cared for by reliable services. The other was public health education. It was reasoned that, given the scientific facts about leprosy, new patients would be prepared to voluntarily seek examination and continue on treatment. It was also reasoned that new patients would be more willing to volunteer if their fear of social ostracism was reduced. It was thought that the social stigma of leprosy in Nepal would be reduced when the public learned the true nature of leprosy.

In 1980-82 a co-ordinated health education programme plan was incorporated into the five-year plans of this part of the NLCP administered by the INF (see map 2).

The educational programme of the 1980s set out to try to bring about changes in community understanding of leprosy, the assumption being that through such change there would be improvement in public attitudes to leprosy, in patient knowledge about their condition and as a consequence in their compliance with treatment.

Groundwork for this study took place in 1980.

One aspect of the NLCP health education programme in 1980 foreshadowed this present research. A community survey of knowledge and attitudes to leprosy was conducted in the district of Nawal Parasi in the south of Nepal's Western Region. The survey was conducted as a prelude to the introduction of leprosy services to that district for the first time. It provided a base-line for comparing subsequent findings after the intensive health education and other activities of the NLCP in the district. In 1990 this survey was repeated as part of this present research project.

In this thesis some comparisons have been made between 1980 and 1990. As well as these comparisons, an up-to-date picture of the variety and intensity of attitudes, and knowledge of leprosy in Nawal Parasi was obtained. This picture provides the context in which to place and better understand the explanations and experiences of individual leprosy patients themselves.

A historic note

Over the last 20 years a new medical service, based on the western scientific medical system, has been introduced alongside the existing traditional Nepali complex medical system. In the early 1970s Nepal began the introduction of a Primary Health Care (PHC) system based mainly on western biomedical concepts but incorporating some remedies from other traditions. Under this Basic Health Service (BHS) each of the 75 districts of Nepal were to have nine health posts, each district capital a health centre or hospital, each of the 14 Zones and four (later five) Regions a hospital. This network of PHC and referral hospitals is meant to make scientific medical services accessible to all the people of Nepal. The NLCP, as it expanded, used the new PHC Health Posts, where they existed and functioned, as the location for case-finding and case-holding services.

Leprosy in Nepal

Leprosy has been specifically mentioned in Nepal's legal code over the years. Provisions are detailed in Chapter 9. Up until recently the law required isolation of patients in a place designated by the concerned government official. Two leprosy asylums (Kokhana and Malunga) were established in 1869 and 1895 respectively (Mali 1966, 1969). These have been closed to new admissions in the last few years. The present law reflects the HMG/N NLCP policy that all patients should be treated as out-patients and remain in their communities as modern medicines render the condition non-infectious within days of beginning treatment.

Systematic Leprosy Control services in Nepal began in 1974-5. They were developed in the western half of Nepal by the INF in co-operation with HMG/N. Other NGOs such as The Leprosy Mission, the Netherlands Leprosy Relief Association, TEAM and the United Mission to Nepal also participated in Nepal's efforts to control leprosy nation-wide.

INF set up LCP in the western half of Nepal.

Between 1974 and 1983 considerable progress was made in establishing the first-ever leprosy control services in Nepal. They were gradually established district by district and included case-finding, treatment and follow-up activities based, where possible, on the Basic Health Services (BHS) Health Post (PHC) network in Nepal. This network was also being newly established at that time. During this time over 200 specialist leprosy health workers were trained and began work; more than 1,000 general health workers of HMG/N were introduced to leprosy and leprosy care; field operational methods were developed and refined; over 4,000,000 of the population were surveyed; and more than 10,000 new leprosy patients were identified and placed on treatment in more than 200 treatment centres. (From current scientific knowledge it is seen as necessary to treat people with leprosy in order to control the disease.)

Compliance: A problem

In Nepal the NLCP requires patients to attend clinics monthly or second-monthly for "supervised" doses of two of the three routine drugs, the remainder being taken by the patient at home. Treatment may need to continue for from six months to over two years.

Case-finding methods

Initially leprosy case-finding was conducted through total *population surveys*. After some years it was noted that patients found by this means were less compliant with clinic attendance than those who had volunteered for physical examination after suspecting they might have leprosy. As mentioned above the case-finding method was changed as a consequence in 1980. *Health education and quality care, aimed at stimulating voluntary presentation of cases*, became the backbone of NLCP.

Base-line data gathered in Nawal Parasi District

The new method of case finding was used in Nawal Parasi District which lies in the south of Nepal's Western Region bordering India on the south. (see map 4).

Prior to the introduction of leprosy control work to Nawal Parasi a Random Sample Survey (RSS) was conducted by programme epidemiologists to establish a *base-line prevalence rate for leprosy* in the area. (This was part of a national survey.) The INF decided to precede the RSS with a survey of *community knowledge and attitudes to leprosy* with findings to be used as a basis for formulation of health education messages, as well as a *base-line for subsequent evaluation of the impact of health education on this population's ideas and practices* in relation to leprosy. As mentioned above this information on community attitudes to leprosy is used in this study for a backdrop and as a basis for comparison of present attitudes.

Non-compliance remained a problem.

It was hoped that the new method of case-finding (through public health education to stimulate voluntary presentation) would reduce non-compliance in the NLCP. However it continues to be of concern. The last ten years' figures show very little, if any, change in the rates of patient regularity and defaulting from treatment. *Defaulter rates* (the percentage of patients on treatment not attending their clinic during that twelve months) have remained between 6%-8%. In 1988 the Director of Leprosy for the World Health Organisation (WHO) still saw compliance as an important issue for Nepal.

A percentage of only six to eight could seem insignificant; however, when related to the number of people represented, it is of concern. In 1989 alone the rate of 7% meant that 615 leprosy patients ceased their treatment. For the life of the LCP (up until 1989), the total number of people who have defaulted could be as high as 1,250. When this figure is taken with those who have been irregular on their treatment (about 3,500) it could mean that some 4,700 leprosy patients have received inadequate treatment for leprosy. This is a sizable and growing number of people. These people are perceived to be at risk of personally experiencing increasing physical deformity, and because they have received intermittent and inadequate dosages of drugs are also at risk of developing drug-resistant strains of leprosy's causative organism, M.leprae. This would constitute a public health risk as well as complicate their subsequent treatment if they return. Compliance is therefore seen as vital to successful leprosy control, particularly since the introduction of a new multi drug therapy (MDT) in 1982.

Compliance in field and referral centres

The NLCP established treatment centres for leprosy in over 200 places in western Nepal. Most of these centres were based at HMG/N BHS health posts. Some were at small or larger hospitals where patients with complications difficult to manage in small clinics could be referred. The main referral centre for the INF LCP is Green Pastures Leprosy Hospital (GP) in Pokhara.

While the LCP as a whole has been relatively successful case-holding results (high regularity and low defaulter rates), there has been a shift in the comparative success of referral centres (hospitals specialising in leprosy care) and the LCP as a whole. Before 1986 the referral centres had better regularity and defaulter rates than the LCP as a whole. Since then the opposite is true. Between 1981 and 1985 the regularity rates at referral centres averaged at 74.6% while the LCP as a whole had an average of 71.6%. From 1986 to 1989 the rate at referral centres was 75% while LCP as a whole went to 77.7%. Defaulter rates 1982-85 in referral centres were 6.2% and 6.6% for LCP as a whole. But for 1986-89 referral centres had a defaulter rate of 7.9% and the LCP as a whole only 6%.

Defaulter rate higher at Green Pastures Leprosy Hospital

In 1988/9 Green Pastures Hospital recorded a defaulter rate of 11.6% while the rate in all referral centres was 7.7%. In the same year the overall rate for the whole LCP was only 7.0%. It seemed that Green Pastures Hospital had a comparatively greater problem with compliance which warranted attention. This Hospital in Pokhara was consequently chosen as the starting point for study in this research.

It is realised that past efforts at health education in the LCP made some common western ethnocentric assumptions. They used a biomedically-derived definition of leprosy which disregarded the definitions of the Nepali people concerned. Problems of communication with patients can be understood to be bound up in the differing medical systems of the communicators and as one feature of complex dynamic changes taking place within Nepal. Medical systems are changing as they are confronted and challenged by the biomedical model espoused by foreign and national health professionals in positions of influence in Nepal. Patients are faced with coming to terms with new ideas and treatments while retaining many of their own beliefs and practices.

Differing explanations of leprosy are held by patients and health workers and the public. The distinction made between illness and non-illness by biomedical science in relation to leprosy and leprosy cure differs from the distinctions made in the Nepali medical system (see chapter 12). Will change in patients' explanations result in better compliance? If so how much and what change is necessary? Would compliance be improved if the health workers and their programmes adopted changed definitions and services? These issues are of vital significance to health educators and health care providers and leprosy patients themselves.

The LCP, in brief, attempted through health education to improve compliance among leprosy patients. The expected improvement did not materialise. Non-compliance continued to be a problem (involving a growing number of people) and had been noticed increasingly at the referral centres, particularly in the Green Pastures Leprosy Hospital in Pokhara. Previously health education took an exclusive biomedical view of leprosy, assuming that if patients' "old" explanatory models were *replaced* by "new" scientific knowledge, better compliance would result.

Nepal: A background summary

For centuries Nepal was a closed land, a land of mystery. After a revolution in 1951/2 deposed the ruling Rana class and placed the King once again in the supreme position, Nepal's borders were opened to the outside world. For more than a hundred years the Ranas had ruled and restricted foreign access to the country. When Nepal opened itself to the rest of the world the people began to be exposed to new developments and different ideas. At that time Nepal began a process of "development" which is still going on. New means of communication, programmes for education, administration, new services in health and so on were established. Economically Nepal is struggling. The World Bank still lists Nepal as one of the ten poorest nations on earth. The Himalayas with their foothills provide a grand spectacle. However, they also form formidable barriers to the development and implementation of new services and programmes like the NLCP.

Geographic variety and population

Nepal lies to the north of India and south of China's Autonomous Region of Tibet. In this mountainous country of the "eternal snows" the land ascends in three giant steps. From the southern plains called the Terrai (100 to 300 metres above sea level), it rises through the central hills (300 to 3,000 metres) to the mountains, with Mount Everest its highest point. These three areas support 36%, 62% and 2% of the population respectively (see maps 3, 5 and 6). In the southern Terrai area and in towns population growth is rapid. The population in the hills is growing more slowly. Malaria eradication (or control) and opening up arable land in the Terrai has allowed people from the hills to re-settle there in large numbers. In the hills rapid growth in population has led to depletion of the forests, and loss of arable land through repeated landslides. The result is that the hills no longer adequately sustain the population. Broadly speaking the hills population is growing more slowly than that of the Terrai. National population growth is 2.6% per annum. The present population is estimated to be 18.9 million, having more than doubled from 8.4 million in 1952-4. Over 90% of Nepal's people are occupied in agriculture, usually in subsistence farming.

Ethnic and linguistic variety

Nepal is ethnically very diverse, having perhaps 70 distinct language groups (see map 3). Until the 1700s there was a series of independent kingdoms in the Nepal hills. This diverse collection of peoples was brought into one administrative orbit in the late 1700s by Prithiwi Narayan Shah, an ancestor of the present royal family. Kathmandu, the capital, administered this mountainous kingdom by appointing its own men as governors in each of the former kingdoms. Local people were kept as lesser officials. A steady process of negotiating followed prior to the imposition of Hindu law and extracting central taxes. In 1832 the process was completed and the first legal code (Muluki Ain) was applied nation-wide. Prior to this not all the Nepali peoples had followed Hindu laws and festivals. "There was great diversity

in cultural background: ... in language; and ... considerable diversity in religious beliefs and practices." (Stiller, 1973a:15). Tucci (1962:89) puts it this way:

The very complexity of the ethnic components of Nepal and the variety of social and religious traditions, together with the existence of tribal organisations that differed from one part of the country to another, made the organisation of the Nepalese people into a caste system more difficult and less rigid than in India proper.

It is unwise to try to describe the typical Nepali. Nepal "... is not and never has been homogeneous in race or civilisation." (Tucci 1962:81). The fact that "... the great variations of environment in this country ... have preserved distinctions of language, culture, ... physical characteristics" (Karan quoted by Stiller 1973:13) leaves the researcher in a difficult position. This thesis does speak of Nepali people and Nepali leprosy patients in general terms but in so doing the underlying diversity remains a modifying factor in any generalisation.

The syncretistic and pragmatic nature of Hinduism has meant that new ideas and ways are combined and merged with old patterns of responding to life in Nepal. In summarising, Stiller (1973) uses a statement from Gurung:

The peopling of Nepal ... was the outcome of successive migrations of Mongoloid groups from the north-east and Caucasoid people from the south-east. Nepal is also the meeting ground of northern Lamaism and southern Brahmanism though most of the tribal groups still cling to the Shamanistic Jhakri cult of mediums and sorcerers. The impact of the Hindu rulers over the last few centuries has been progressive "sanskritisation", and the establishment of Indo-Aryan Nepali as the *lingua franca* of the Kingdom (1973a:14).

Stiller (1973a:15) goes on to observe of the background of modern Nepal that "There was great diversity of cultural background: there was great diversity in language; and there was considerable diversity in religious belief and practice".

A Hindu nation with a variety of religious traditions

The Legal Code of Nepal enshrined in law, principles of the Hindu hierarchical caste system, and concepts of ritual purity and

pollution, with ceremonies and punishments related to breaking these laws. These laws relating to caste were removed from the Muliki Ain in 1963 (Bista 1991:44). It is the only country in recent times to have based its legal code on Hindu philosophy and practices. The Hindu world view was the basis of Nepal's laws and continues to form the context of everyday life for many of its peoples. Subsequent to the advent of the National Legal Code all Nepali people, no matter what their previous background, were subject to these laws and festivals. Some people, however, managed to retain their own older ways as well. For example, some groups were able to negotiate the retention of some of their old customs (such as eating beef) even where these contradicted the Hindu law. This process of Hinduisation of all Nepal established, to a great extent, the supremacy of the high caste Hindu as leaders of religious, ritual, administrative and political life in Nepal.

Buddhism

Nepal is not only a Hindu nation, it is also the birthplace of Buddha. In Kathmandu, for instance, a unique mix of Hindu and Buddhist temples and festivals can be found. Many of the hill peoples of Nepal follow basic Buddhist philosophies, but with an overlay of Hindu observances. Nepal's Buddhism is not only extremely ancient, it is now receiving return interest from newer Buddhist centres in Tibet and other parts of Asia.

Islam

A small minority of Muslims is present in Nepal. Some of them entered Nepal in the 1700s as skilled artisans for ruling houses. They were mentioned in the legal code as one of the low castes. This indicates how Hindu Nepal accommodated them. The Muslims themselves have retained distinctiveness in the midst of their syncretistic neighbours. They observe their own religious practices using the Koran instead of the Vedas. They also maintain links with the rest of the Muslim world.

Christianity

Since the 1950s Nepal has allowed Christians to reside in the country. A small but growing number of Nepali people who follow the Christian way can be found. Many new health programmes and institutions in Nepal, both for leprosy and general, were begun by Christian missions such as the INF, which began work in Nepal in 1952/3.

Secularism

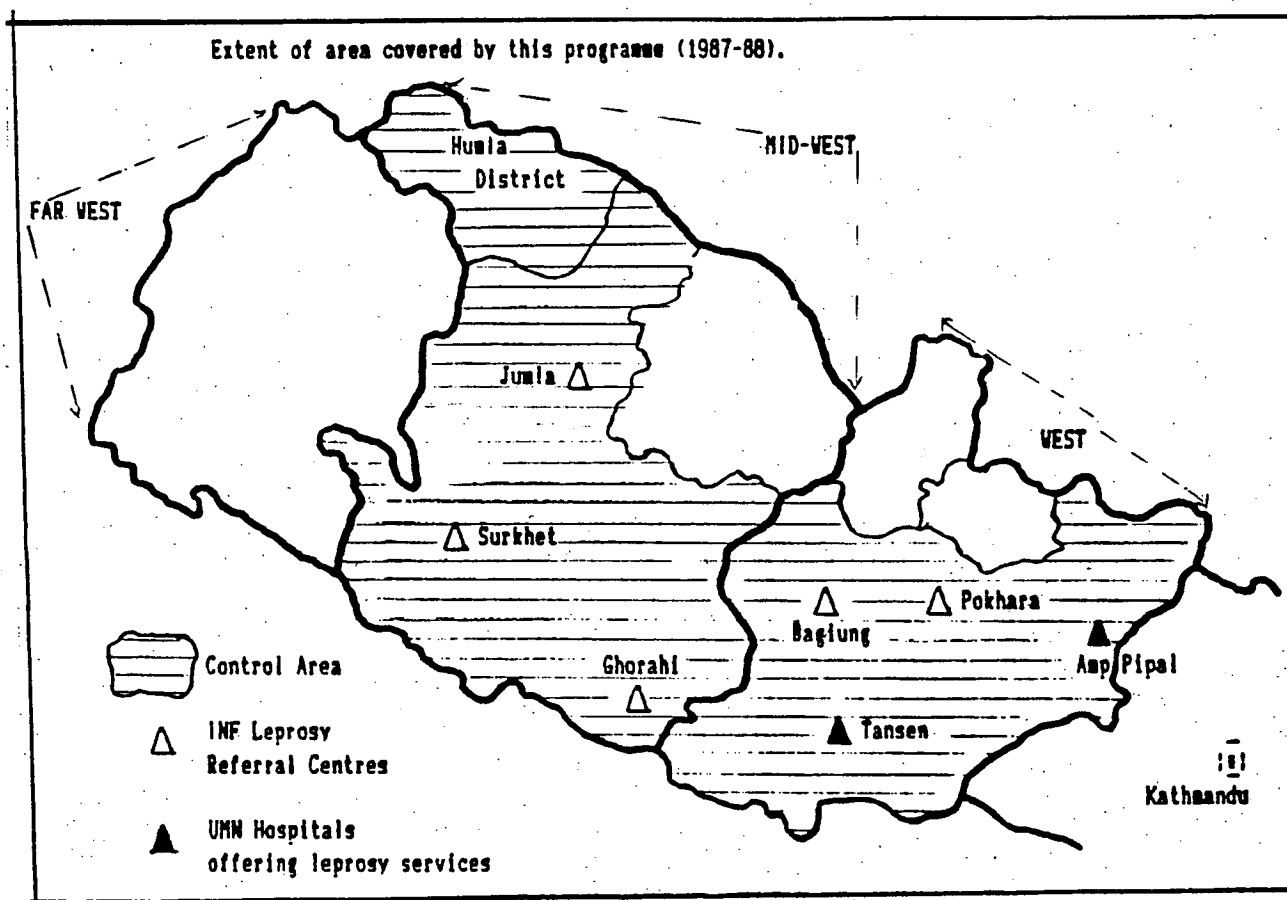
A gradual process of secularisation has also been taking place in Nepal over the last 40 years. This would appear to have been mainly through the influence of foreigners from western countries. Ideas of *secular scientific* origin come into Nepal through the development process. The national education system of schools, begun in the early 1970s, mixes them with the Hindu. Higher education programmes such as nursing, medical and other health worker education are based on western biomedical, secular scientific concepts.

The National Census of 1981 reported Hindus to be 89.5%, Buddhists 5.3%, Muslims 2.65%, Jains 0.062%, Christians 0.026% and "Other" religions 2.46% of the population.

It is against this background, and through an ethnomedical approach, that the perspective of Nepali leprosy patients themselves is seen as they relate their experiences of leprosy. A discussion of the methodology, and description of how data - from which these perspectives became clear - was gathered and analysed follows in Chapters 4 and 5.

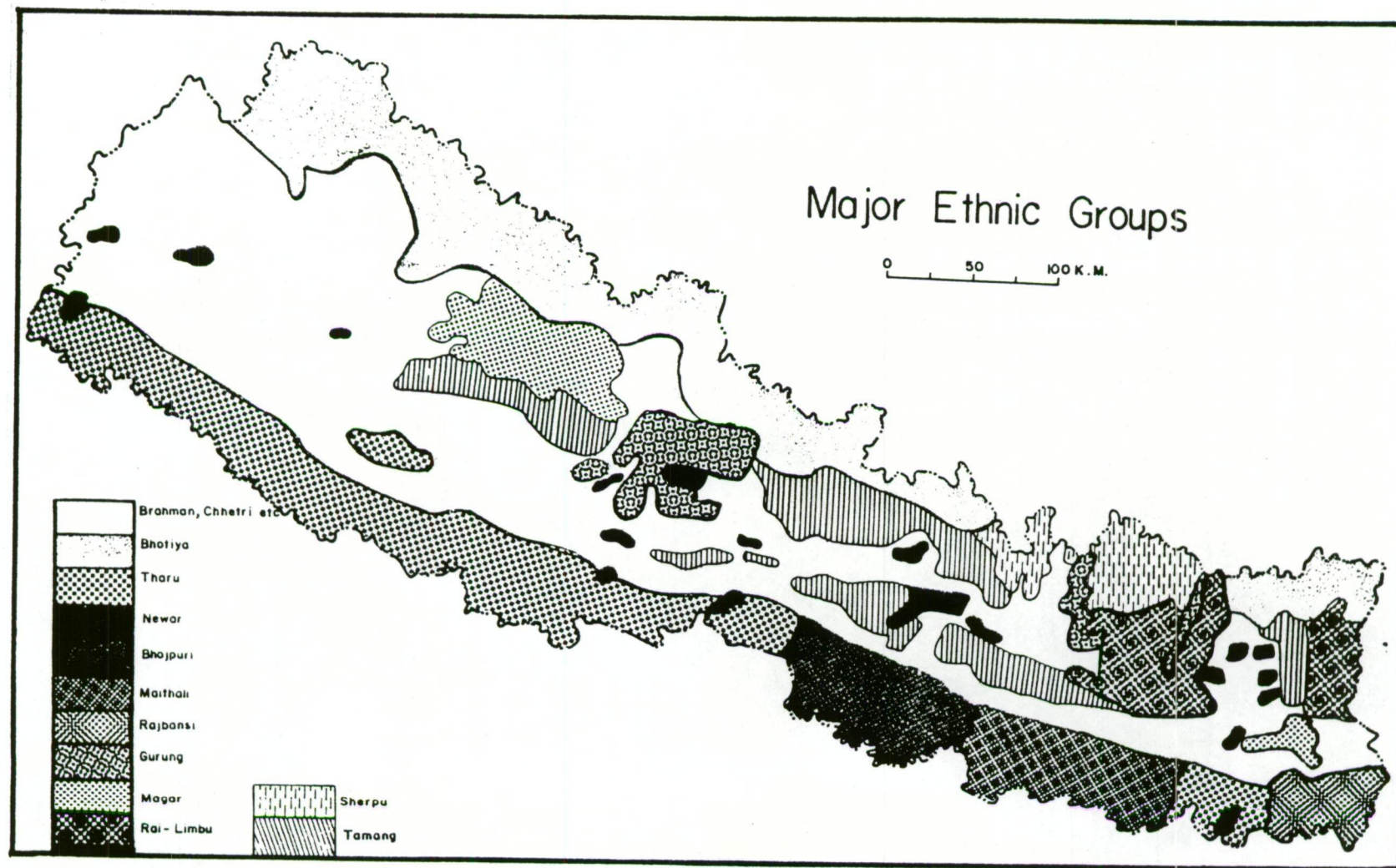
M A P 2.

Areas covered by INF
LCP in Western and
Mid-Western Regions
on Nepal in 1987/88
(INF LCP 1987/88:4)



MAP 3.

Nepal's Ethnic
Diversity
(Shrestha 1988:48)



Major Ethnic Groups:

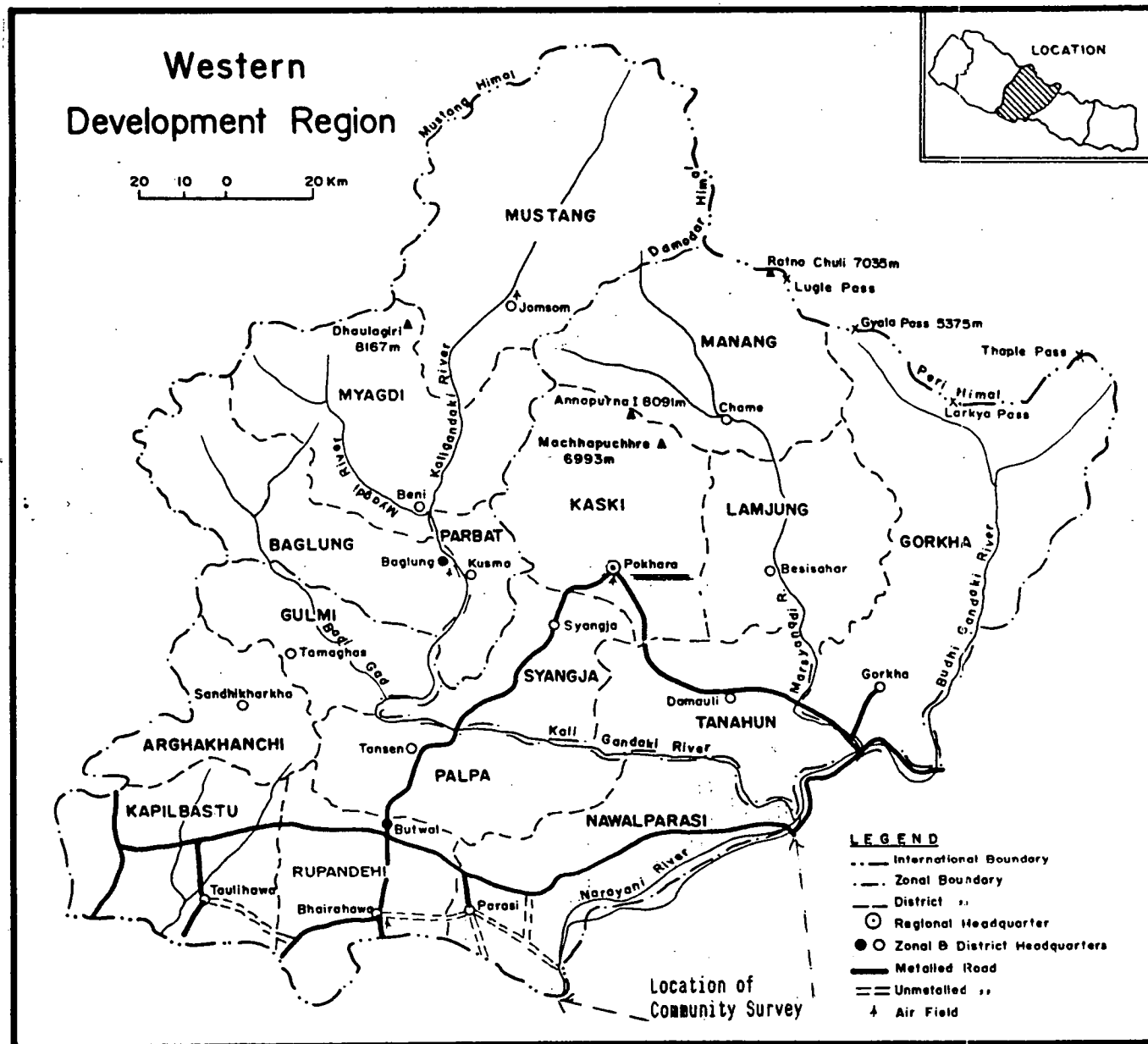
In fact, there has been no detailed country-wide survey on the ethnic groups of Nepal. On the basis of mother tongue statistics, Nepali-speaking group such as Brahman, Chhetri, Thakuri, etc. shares over 58% of the total population. It is followed in a descending order by Maithili, Bhojpuri, Tamang, Tharu, Newari, Awadhi, Magar, Rai, Gurung, Limbu and Sherpa representing from 12% to 0.1% approximately. The above map reveals the core areas occupied by various ethnic groups.



ETHNIC DIVERSITY IN A BHOJPUR SCHOOL

These children at a school bench in eastern Nepal give an idea of the racial variation in Nepal: besides Mongoloid faces there are finely-shaped physiognomies of Caucasian type.

From left to right:
Rai (ancient Nepalese people),
Brahmin (Caucasian priestly caste),
Chetri (Indo-Nepalese mixed caste),
Thamang (ancient Nepalese people) and Sunar (Kami, professional castes of the smiths and goldsmiths).
(Hagen 1980:114)



MAP 5.

Nepal's Elevation

Zones

(Shrestha 1988:19)

Topography of

Control Area.

(INF LCP 1987/88:4)

Topography of the Control Area: a cross section of Nepal -- South to North

South <-----> North

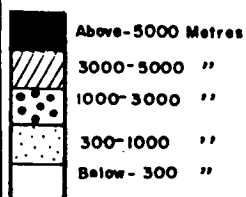
Altitude

- 8000

- 6000

- 3000

Sea Level



Contour in Metres

Teral

100 - 300 m

(36% of Pop.)

Central Hills

300 - 3000 m

(62% of Pop.)

Mountains

3000 m +

(2% of Pop.)

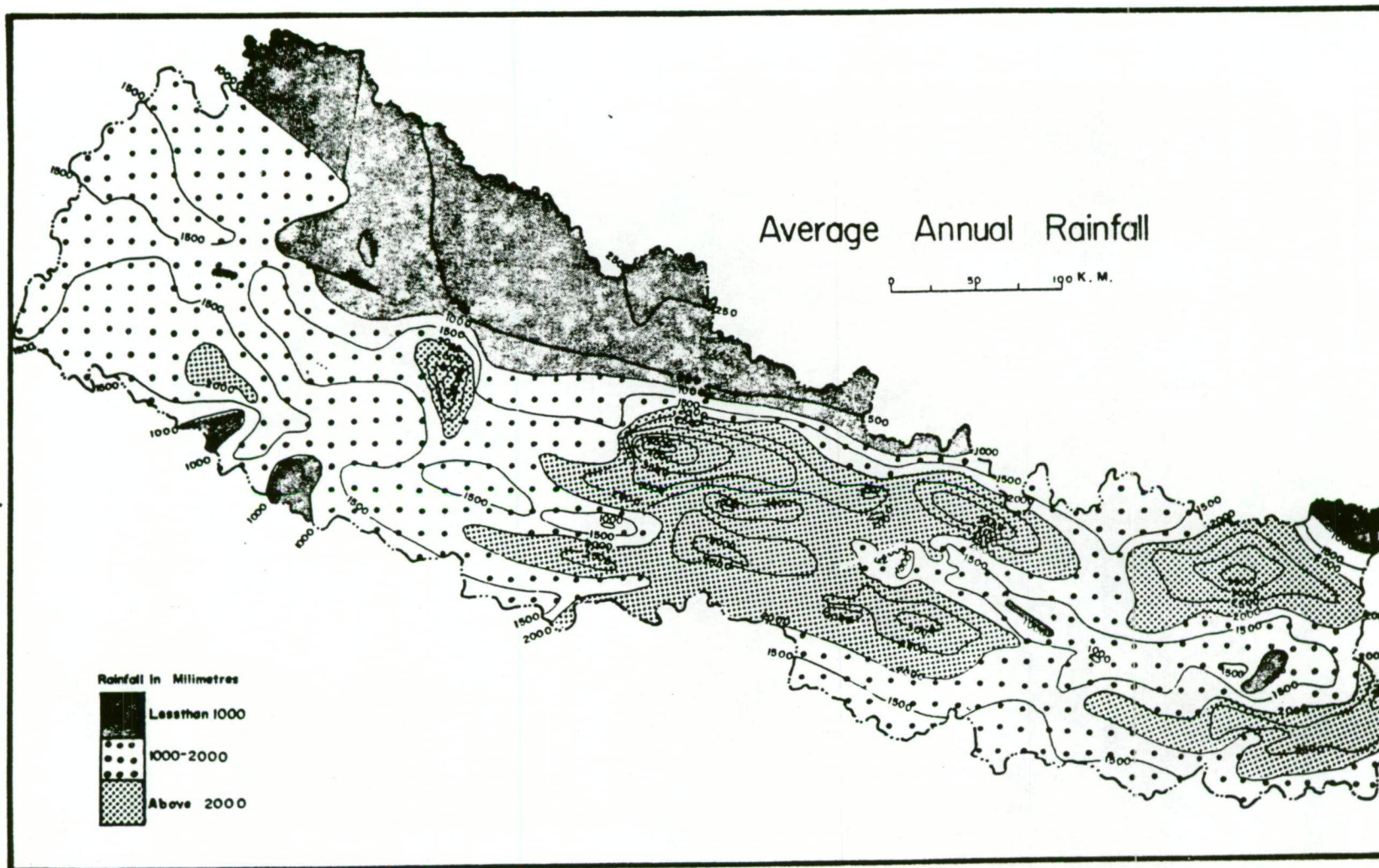
Travel is easy on the Teral where an estimated 36% of the population lives. For the majority of the population living in the central hills, most travel must be done on foot over rugged mountains.

Elevation Zones

0 50 100 K.M.



Nepal: Average
Annual Rainfall
(Shrestha 1988:25)



Annual Rainfall:

The annual rainfall in Nepal varies from place to place, ranging from less than 250 millimetres in the Mustang area of the Central Himalaya to more than 4,000 millimetres at Lumle near Pokhara. The rainfall generally decreases from central part towards west. In the north, there exists a large rain shadow area beyond the great Himalayan Ranges in the central and western parts of Nepal. It is the area of lowest rainfall in the country. Moreover, there the precipitation occurs mostly in the form of snow. Locally, south facing slopes receive higher rainfall. There are certain pockets receiving higher rainfall and these are located mainly in central and eastern sections. The regional distribution of rainfall in Nepal is not, however, guided by any specific factor. Most rain occurs in the months of June, July and August. April and May are generally dry months.

CHAPTER 4 : RESEARCH METHODOLOGY

Introduction

Having in the the last chapter identified the problem and described some of the complexity and ambiguity of the setting in which the problem exists and in which it must be studied, this chapter turns to a discussion of methodology, to "... the ways in which we approach problems and seek answers" (Taylor and Bogdan 1984:1).

In medical science many assume that experimental, randomly controlled trials are essential to sound research. In the social sciences there are two main theoretical perspectives. The **positivist** approach "... seeks for *facts* or *causes* of social phenomena, apart from subjective states of individuals." Thus they adapt a "... natural science model of research ..." and "... search for causes through methods such as questionnaires...that produce data amenable to statistical analysis". On the other hand the **phenomonologist** is "...committed to *understanding* social phenomena *from the actor's own perspective*". Thus they seek understanding through qualitative methods such as participant observation, in-depth interviews and others that yield descriptive data ..." striving to understand "... on a personal level the motives and beliefs behind people's actions ..." (1984:1-2).

This study predominantly uses approaches from phenomonology although those from other perspectives are also utilised.

Part 1: DISCUSSION OF CHOICE OF RESEARCH DESIGN AND METHODS

The search for design and method applicable in a cross-cultural, third-world setting: Qualitative and quantitative approaches combined

The social scientist working in a medical field of enquiry is faced with a paradox and a dilemma. This discussion traces these problems and explains the background of the choices made in relation to research design and methods considered to be generally suitable for this research problem and setting.

In the past it seems that the disciplines of sociology and anthropology have struggled to be recognised and accepted in the broader scientific world. Social scientists sought to apply the same sort of rigour and method in seeking for laws or general patterns in the world of human beings living together in the social and cultural arena that are held to apply in experimental scientific research (Good and Hatt, 1952; Kaplan, 1964; Cohen, 1979). In the opinion of some this has led to poor quality social science research being undertaken on the international scene. For others (Green, 1979), these constraints have represented an impossible straight-jacket. The dealing with these constraints in the real world has for some provided an opportunity for innovation and development of new designs and methods of data-gathering and analysis (WHO, 1981a). Yet the difficulty remains. New methods developed in the disciplines of social science remain largely unfamiliar, and consequently not generally acceptable to medical science (Eisenberg and Kleinman, 1981; Foster, 1987). Even though advances have been made in the development of research design and methods which combine qualitative and quantitative approaches and which are realistically applicable in socio-cultural and inter-disciplinary international settings, the difficulty of having these acknowledged and their findings accepted by medical science people remains (Mair, 1972; Foster, 1982, 1987; Barnard, 1988; Najman, 1989).

A combination of methods is used in this research in the hope that this gulf may be bridged. Perhaps the application of flesh and blood to the dry bones of a traditional compliance study will encourage medical people engaged in leprosy control to form more realistic expectations of social science research and of their clients and programmes. Perhaps it will also result in their entering enlightened partnerships with the patients they serve. Some indication of this already beginning is gained from the recent studies in Pakistan, Thailand, India and Indonesia, which look into socio-cultural aspects of leprosy. These were reviewed in Chapter 2.

The qualitative-quantitative continuum

Najman (1989) at a seminar on research design dilemmas proposes a continuum between qualitative and quantitative methods of social research. He suggests that qualitative research methods generate hypotheses and that research designs can be graded from qualitative to quantitative thus:

1. Observation and related qualitative data collection (e.g. participant observation, case studies);
2. Unstructured interviews, focussed groups;
3. Analysis of documentary and historical sources;
4. Analysis of official statistics;
5. Quasi-experimental and experimental studies; and finally
6. Cohort, longitudinal studies and the like, which are hypothesis-testing and quantitative.

The ideal design for scientific research is often held to be randomised controlled trials. But one seminar contributor pointed out that employing such trials for some research subjects was like taking a sledge hammer to crack a walnut! Newell (1989:6) suggested that qualitative research may be included in randomised controlled trials so that "...an appropriate and coherent near-to-complete description..." can be supplied. He went on to say that each approach can learn from the other: "The ideal interplay between qualitative and quantitative methods occurs when individuals from the caring, the numerate and the social sciences work together ... with parity of esteem".

Even in the presence of these protestations there remain those who continue to view experimental, scientifically controlled methods as absolutely essential to sound research. For Foster (1987) this is a lamentable real-world constraint which results in poor quality social research being done on the international scene, where there is over-concern about design elegance and less concern for practical application of results. For Green (1979) the real-world of community and health education programmes requires that adjustment be made to ideal designs for evaluation and research without which the results cannot be generalised to actual situations.

This thesis adopts the stance taken by scholars who have called for qualitative, rich, situational descriptions, such as those employed by anthropologists and labelled ethnographic techniques, to supplement or replace traditional research approaches to evaluation of programmes in health and health education. An ethnography is a description where the researcher tries to render a 'true to life' picture of what people say and how they act and where "...people's words and actions are left to speak for themselves" (Taylor and Bogdan 1984:124).

A pivotal assumption for ethnographic approaches is that individual behaviour is guided by meaning structures and that understanding those meanings requires understanding the relationships between what a person says and does in the natural setting in which the behaviour occurs (Cohen 1979:158-9).

Compliance studies: Changing approaches in the field of health and health education research

Researchers in the medical field have in the past tended to overlook the power of ethnography and carried out many studies in the hope of finding such orderliness in their searching for patterns and indicators of patient compliance and non-compliance. A 1979 publication reviews many studies. Cohen (1979:153) summed up the matter by saying:

Social scientists, guided by the spectacular advances in the physical sciences, during the past century have adopted the metaphors and methodologies of experimental research - hoping to find laws of human behavior equivalent in scope to the laws of the physical universe...generations of researchers were trained with the expectation of developing comprehensive theories that would both explain and predict human behavior. Our expectations, steeped in the traditions of physical sciences, lead us to assume that general laws will emerge from our investigations of aspects of human behavior, such as patient compliance with medical regimens.

Frustration has resulted from the long search for general laws or predictors of compliance behaviour, which will present a coherent structure. No such regularities emerged. Cohen concluded that research into patient compliance has yielded "... fragmentary notions as to the determinants of compliance ..." (1979:153).

It seems the compliance studies reviewed by Cohen assumed two things. They expected that "... lawful human relationships will

transcend the idiosyncrasies of the particular context.." (1979:154), and they assumed that "... useful suggestions for practitioners *must* rest upon an unambiguous and small set of empirical generalisations" (1979:153). However, few clear and consistent laws and generalisations were found in relation to patient compliance. "Features of the regimen and socio-behavioral characteristics of the patients were the most consistent predictors of compliance" (1979:153).

Cohen suggested a change of direction and method. He suggested that the search for general laws is misdirected and proposes instead to search for meaning of behaviour in its particular context maintaining that "... human behavior is comprehensible only in terms of contextual relationship" (1979:154). He in fact suggests an **ethnomedical approach**; that is, through a more culturally relative approach the researcher seeks "... to understand how people go about the task of seeking, describing, and explaining order in the world in which they live" (Taylor and Bogdan 1984:11). It is a search for values and meaning in context, and goes beyond observation of social action towards an understanding of the meaning behind those actions.

That the "grandiose goals" of finding general laws of compliance were not fulfilled has been explained by the youth of social science and the difficulty of conducting valid research using human subjects. The difficulty of applying experimental control in the real world and what it does to the results is discussed by many scholars and researchers. They have expressed their sense of constriction and frustration when functioning in a climate dominated by opinions biased on one side of science.

Practical and acceptable research design: A dilemma

Lawrence Green, one of the leading health educators in the USA, writes of the paradox faced by would-be health education evaluators. He subscribes to the notion that experimental control is the ideal. However, he has learned, through personal experience and observation an important principle of health education evaluation namely that "...experimental control is an elusive ideal that cannot be reached without sacrificing some

generalisability of the results" (Green in Cohen, 1979:142). The reason for his coming to this conclusion lies in the fact that "...the laboratory conditions necessary for complete experimental control create such artificial conditions on programmes that the results cannot be generalised to actual situations" (142). After discussing various methods and designs devised by social scientists to cope with the reality of not being in a laboratory and to allow for lack of control he comes to a paradox.

Green gives voice to the position of those social scientists and researchers who seek a practical understanding of phenomena such as compliance behaviour. Such insights may be requested by clinicians, however, when provided they are likely to be rejected by them because physicians are, as he puts it

...less experienced with quasi-experimental designs developed largely in educational and socio-physical research ... Hence, physicians do not trust these methods and are sometimes unco-operative with evaluations which employ them. We are then left with a paradox: we have too little control over the health-care system or health resources to exercise true experimental designs that would be acceptable, and we cannot get enough co-operation or support for quasi-experimental designs because they are unacceptable. (in Cohen 1979:147)

This problem of reconciling the practicability of experimental research design and the lack of acceptability of quasi-experimental research design is evident in other writings on health sciences and evaluation. For instance, in 1981 a WHO workshop was held on appropriate technologies for behavioural science research on health problems. The context was international health, particularly in south Asia. The disciplines represented ranged from medical doctors, anthropologists, nutritionists, to sociologists and health educators. Reasons were discussed as to why so little operational health research had been conducted in their countries. Participants concluded that the principal reason was "... the near-exclusive reliance on survey techniques", survey research being emphasised in part because some researchers feel it is more "scientific" than observational techniques, and in part because medical doctors prefer it because to them "...

qualitative information on human behaviour ..." is suspect (WHO 1981a).

Foster observes that many behavioral scientists who apply for funds to conduct health-related field research from agencies like the World Health Organisation "...conform to the expectations of research committees, stressing quantitative methods and slighting the qualitative approaches that often are more productive in providing operational information". Foster regards it as unreasonable

...for medical doctors to exercise the same degree of control over behavioural proposals (as they do over medical research proposals): behavioural research does not conform to a biomedical model, it cannot be judged by the same criteria, and relatively few medical doctors really understand appropriate behavioural research methodologies (1987:713).

Eisenberg and Kleinman also address this issue in their introductory chapter on the relevance of social science to medicine, contending that "...too narrow a view of the sciences relevant to medicine" (1981:11) prevents progress and impedes further understanding in medicine.

They acknowledge that biomedical sciences have contributed greatly to more effective medical practice, however they point out that the disease-centred view held in medical practice "... completely overlooks the complexity of the processes leading to the decision to see the doctor; ...the decision to become a patient". They see patienthood as a social status not simply a biological one. In order to understand it, therefore, *non-biological* variables must be taken into account (1981:13). They consider that medical sociology must supplement the role of biological sciences in the theory and practice of medicine with "... an equal application of the social sciences in order to provide a more comprehensive understanding of disease and better care of the patient" (1981:11).

An important contribution is also being made by medical anthropologists, "We have tried for many years to demonstrate what good behavioural research has to offer health programmes ...", writes Foster (1987:717):

...qualitative methods are...relevant to behavioural research on health problems...hypothesis-testing by...survey research ...by no means the only acceptable form of...proposal.

Foster, in reviewing the range of diseases and problems which anthropology addresses, mentions specific diseases like leprosy. Problems such as 'case-holding' (compliance) in immunisation, tuberculosis and leprosy control programmes would benefit from anthropological input, for example being able to say something "... about the dynamics of case-holding ... how can leprosy patients be ... persuaded to accept therapy?" He suggests that health educators are sometimes subject to the same bias towards a biomedical model as their medical colleagues and that anthropology has a contribution to make towards effective health education. He believes that anthropological research can

... play an important role in improving health education ... Our knowledge of ethnomedicine is critical to this role; we must demonstrate to health educators exactly how a knowledge of prevailing health beliefs and practices must be the starting point in planning health education campaigns. Health education efforts sometimes fall short of targets, I believe, because of the assumption that knowledge of skills in using *communication* devices is the central element in the profession. To be fully effective communication skills *must be coupled with* ethnomedical information. (Foster 1984:852)

In utilising insights gained from medical anthropology this study seeks to gather knowledge of leprosy in Nepal from an *ethnomedical* point of view; that is from the point of view of how groups in Nepal handle the illness, disease and sickness of leprosy from their own cultural perspective; and through this knowledge to contribute to the improvement of related health education to the problem of compliance.

The study does not limit itself however to consideration of individual behaviour changes: it also considers the epidemiology of the disease, the services, structures and processes of health delivery and the training of health workers. As this study seeks to draw out implications for changes in health delivery structures, Foster's next remarks are of particular relevance.

It simply does not occur to many health administrators that at least half of the problems encountered in providing health care to traditional peoples are bureaucratic in nature. Other administrators are quite aware of bureaucratic

problems, but they *assume* that the mode of operation of a bureaucracy is a given, something incapable of major modification. From this it follows that if changed behaviour is essential to improved health levels, it must be the individual and community, not bureaucratic behaviour that changes. (Foster 1984:853)

Contending definitions and meanings of social action in relation to patients illness careers, compliance and 'cure', held by individuals and by workers in health delivery systems, are central concerns of this thesis. For change to occur our vision must go beyond the individual to focus on their social and cultural context, accepting that the health bureaucracy is as legitimate a target for change as the patient whom it serves.

The benefits of an inter-disciplinary approach

All the arguments cited above for changing research methodologies confirm the need for interdisciplinary approaches. Jake Najman of Queensland claimed that in efforts to address issues of political and social significance, "we will only succeed...and 'get it right' if we understand and adapt (but not always adopt) the scientific method of research" (1989:46). He mentions Mechanic who, in 1989, pointed out that the opponents of each methodology would be wise to incorporate into their work the strengths of the other.

Both Foster (1984 and 1987) and Mair (1972:297) stress the desirability of anthropologists for instance being part of interdisciplinary health teams where they work with them in the health system as participant observers and obtain knowledge of their socio-cultural system. Similarly, anthropologists may take part in training of specialist team members who will work in cross-cultural situations. Thus their knowledge of the ethnomedicine of the new country and skills in social research are passed on. While this present research did not actually have an interdisciplinary team working on it it does approach the topic in a trans-disciplinary way, partly because of the varied interests and expertise of the researcher.

"Medical anthropological research requires knowledge of two socio-cultural systems: the client community *and* the health care

system" (Foster 1984:853). This study approaches the phenomenon of leprosy in Nepal from the point of view of Nepal's ethnomedicine and traditional beliefs and practices, as well as from the point of view of a health care system set up to deal with it which is based on a western scientific definition of the problem. The study therefore discusses these two socio-cultural systems.

While Foster was pleading for medical scientists to broaden the scope of what they regard as convincing evidence (Foster 1982, 1987), Barnard (1988), an anthropologist himself, appeals for anthropologists to reciprocate. According to him anthropologists should be "... capable in large numbers, of conducting quantitative research *in addition* to the qualitative work ...". This would require thinking in terms of experiments, control and comparisons.

Every time a government ... decides to institute a programme *here* and not *there*, a natural experiment is under way. Those who are trained in scientific methods to evaluate the results of these natural experiments, and who have the humanistic training to appreciate the importance of information extracted from the social world by scientific means, will produce important knowledge. It is my hope that anthropologists will be among those who do. (Barnard 1988:26)

Mair suggests that anthropologists "share in the training of those going to work in peasant societies" (1972:297), but that they no longer offer to the specialist teams blueprints, rather maps - "a map on which the dangerous passages and obstacles to communication are marked in red"; that they should attempt to account for resistance to change rather than give recipes for bringing it about. She suggests that the anthropologist

... can explain *why* obvious improvements in technique are not accepted as soon as they are demonstrated; *why* people are not moved by arguments the validity of which is not in doubt. Impatient development (or public health) workers blame this on the stupidity or the laziness of their 'clients' - assuming...that any man should be expected to respond to a rational exposition of reasons why he should change his mode of behaviour. (Mair 1972:297)

Health workers may explain rationally the reasons why a leprosy patient must take the medicine regularly, must come on time to

get the medicine and so on, assuming to effect an immediate change in patient behaviour. When this does not happen they become frustrated and the patient is blamed. The staff of the Leprosy Control Programme when asked about the typical irregular patient offered a list of character weaknesses.

When planning aims at technical improvement, and when this improvement implies that people change their behaviour in some way, the anthropologist has something to say: that knowing the people you are working with - and knowing them in the particular way that the anthropologist does - is just as important as the superior expertise of other technicians involved. For example, knowledge of the community beliefs and practices about leprosy is vital as is the clinical expertise knowledge of the pathogenesis of *M. leprae* of the leprosy physician.

But community beliefs and practices are not static. Mair points out "... that the year or two that an anthropologist spends in the society ... is not long enough ... to observe any appreciable change ..."; what is seen has to be described "... as if it were static". The observations of that socio-cultural reality made over a year or two will reveal "... ambiguities in the rules ..." that the majority of the members of that society profess to obey (Mair:1972:270). Thus changes may take place over a period of time as the rules relating to structure of the society - which some would regard as fixed - are followed to a greater or lesser degree. The ambiguities found through continued observation may indicate the extent of the dynamics of change present in that society at that moment or may also reflect the heterogenicity of the community under study. This the case in Nepal with its complex ethnic and cultural mix, which is undergoing social and technological change under the impact of 'western' ideas.

Time span of this study in a change situation

Mair's comments are pertinent to this study. The thesis field work study took place over 24 months. The first period of observation and data-gathering was between February and December 1990, the second between October 1991 and February 1992. The period of general study, however, covered much longer than that.

The community study took 12 years. The first surveys were conducted in 1980 and the last, the follow-up surveys were completed in February 1992. In the cohort study of patients records from the past four to five years were reviewed. Some of them had been leprosy patients for over twenty years and their experiences are recorded.

The study as a whole therefore presents longitudinal data against which to set and interpret the more immediate evidence of the interviews. In this way it is believed that a more dynamic and phenomenological view is presented than is possible through a traditional health programme evaluation of compliance study.

The emic-etic distinction and choice of study methods

Anthropology is also useful in providing guidelines for the design chosen for this study. That is the distinction between emic or *insider* and etic or *outsider* data (Harris 1968). Pike in 1954 and 1962 suggested the emic and etic dichotomy. The terms come from linguistics. Emic comes from *phonemic* and suggests "structural results" and must be related to the actor's meaning, while Etic comes from *phonetic* and suggests "non-structural results" and relates to outsider descriptions.

Harris (in Mair 1972:571) proposes the following definition of emics:

Emic statements refer to logico-empirical systems whose phenomenal distinctions or "things" are built up out of contrasts and discriminations significant, meaningful, real, accurate, or in some other fashion regarded as appropriate by the actors themselves. An emic statement can be falsified if it can be shown that it contradicts the cognitive calculus by which *relevant* actors judge that entities are similar or different, or in some other sense *appropriate* or *acceptable*.

Harris also offers a definition of etics:

Etic statements depend upon phenomenal distinctions judged appropriate by the community of scientific observers. Etic statements *cannot* be falsified if they do not conform to the actor's notions of what is significant, real, meaningful, or appropriate. Etic statements are verified when independent observers using similar operations agree that a given event has occurred. An ethnography carried out according to etic principles is thus a corpus of predictions about classes of people. Predictive failures in that corpus require the

reformulation of ... description as a whole. (575)

Pike quotes extensively from Edward Sapir (1927) as follows:

It is impossible to say what an individual is doing unless we have tacitly accepted the essentially arbitrary models of interpretation that social tradition is constantly suggesting to us from the very moment of our birth. Let anyone who doubts this try the experiment of making a painstaking report (i.e. an etic one) of the actions of a group of natives engaged in some activity, say religious, to which he has not the cultural key (i.e. knowledge of the emic system). If he is a skillful writer, he may succeed in giving a picturesque account of what he sees and hears, or thinks he sees and hears, but the chances of his being able to give a relation of what happens, in terms that would be intelligible and acceptable to the natives themselves are practically nil. He will be guilty of all manner of distortion; his emphasis will be constantly askew. He will find interesting what the natives take for granted as a casual kind of behaviour worthy of no particular comment, and he will utterly fail to observe the crucial turning points in the course of action that give formal significance to the whole in the minds of those who do possess the key to its understanding. (Pike 1962)

Pike indicated that "emic structure must correspond to the action's "purpose" during the observed performance, that is an emic description must be related to a set of logico-empirical procedures by which the actor's meaning and purpose is made known. Harris quotes Pike: "In spite of the problems which are involved, it is absolutely essential if one is to study behaviour as it actually functions, that one assumes that the analyst can detect the presence and to some extent the nature and meaning of purpose." (Pike 1954:80) Harris also suggests that "...the predominantly emic corpus of extant ethnography must be supplemented by etic descriptions." (Mair 1972:569)

To one come lately to medical anthropology out of the thinking of medical science, nursing and public health the distinctions between Emic and Etic information, the need for *insider* and *outsider* verification of data, seem to parallel qualitative and quantitative methods and of internal and external validity. They also seem to be reflected in distinctions between "hard" and "soft" data, the appeals for medical scientists to open their minds to "soft" data as acceptable evidence (Foster 1984, 1987) and the call to anthropologists to include the conduct of quantitative research among their capabilities (Barnard 1988).

It seems elementary that the interpretation of words and events observed and noted in another culture needs *the cultural key* for the unlocking of their significance and meaning, so that they can be related intelligibly to those who do not possess knowledge of the emic system concerned. For such cross-cultural understanding one's own world view gets in the way. When this is recognised then an attempt can be made to suspend judgement and perhaps the *insider* meaning can be uncovered. In this study the material gathered through observation and interview is approached as an emic description in that there was considerable effort to uncover the *insider* meaning. The cohort study is essentially etic in nature and the community study while being etic is interpreted from an emic viewpoint.

An African study of leprosy reported in *Leprosy Review* in 1979 put into practice a **balance or combination of methods** of approach similar to those chosen for this study. This study was carried on over a three-year period with a team of five expert researchers. They found their in-depth interviews "far more rewarding than our quantitative study of medical records - both for ourselves and, we feel, for the doctors...". Varkevisser concluded that "...although the various methods we used all had drawbacks as well as merits, *in combination* they worked well". It is with the hope that such combination would work well for this study that its methods were chosen (Varkevisser 1979).

Ethnomethodology does not claim to be appropriate for *validating* hypotheses but can "... *suggest new relationships* by discerning why previously assumed relationships failed to hold consistently" (Cohen 1979:159). Cohen believes that while combined approaches will create some problems because of adding an observer in an experiment, "...they may identify factors causing the patient's non-compliance with the regimens..." (1979:160). It is precisely because ethnomethodological and ethnographic techniques hold potential strength for gleaning "...important contextual relationships that might easily be overlooked in controlled experiments" (Cohen 1979:159) that they are chosen for this study.

The ethnographic techniques used in this thesis provide a descriptive account of what people said and did. They essentially yield an 'outsider' view which does not move into the world of social meaning of those so described. The 'insider' view which reveals meaning as seen by the actors themselves is provided through ethnomethodological techniques. In the particular task of exploration of this world of meaning relating to leprosy and uncovering the layers of sociocultural reality the ethnomethodological approach is applied as ethnomedicine. Thus the point of view of the groups and individuals are revealed as they relate to the presence of leprosy as illness, disease and sickness in their own cultural context. This ethnomedical approach to understanding what is observed by the researcher as 'outsider' guards against interpretations being constantly askew by allowing 'insider' knowledge to be uncovered.

Part 2: RESEARCH PERSPECTIVE ADOPTED AND STUDY HYPOTHESES

Ethnomedical approach

The purpose of the research is both theoretical and policy-oriented with implications for health education in terms of examining assumptions and gaining insights for future planning. The study deals with education in a cross-cultural, international, and health care setting. Education itself draws upon various of the social and behavioural sciences. Health education in a cross-cultural health care setting of necessity enters the medical anthropology or ethnomedical science areas as well as keeping in touch with public health, epidemiology and biomedical science. Because of this the design and choice of research methods for this research emanate from and embrace this breadth of interests.

This research on socio-cultural aspects of leprosy aimed to pay equal attention to the social and cultural determinants of health status and to gain an understanding of health and illness which is necessary for effective preventive and therapeutic measures. The medical sciences continue to work hard in leprosy research to find better and better answers to medical problems. There remain, however, perplexing questions which are related to

human behaviour. The problem of compliance is one of these, as discussed in the literature review. An increased application of social science in this perplexing area holds out hope for provision of both a more comprehensive understanding of the "illness", "disease" and "sickness" of leprosy and better care for the patient (Eisenberg and Kleinman 1981:ix).

In this study an **ethnomedical approach** predominates. Each person's "scientific" or traditional medical background is conceptualised as the ethnomedicine of that person's culture. In conducting the study a conscious endeavour was made to set aside pre-conceived or ethnocentric ideas and to suspend judgement or interpretation of what was said and done by informants. In other words an attempt was made to listen, to look and see what was there, with the mind open to other ways of understanding. Taking this approach has resulted in glimpses of another world, of other medical systems with their different ways of defining illness and of dealing with it. The resulting "thick description" (Geertz, 1973:54) and ethnomedical interpretation of what it is like to be a leprosy patient in Nepal enables us to view through the leprosy patient's eyes what professionals call a compliance problem. In turn this gives insights into how health education programmes may be better focussed and managed.

An observational, descriptive and analytical study

According to an epidemiological decision-tree model, this study as a whole can be designated both observational and descriptive. It is observational in that it does not involve intervention or experiment (although data are collected specifically through interviews). It is descriptive of social actions and meanings, providing cultural and value frameworks in which to understand social phenomena (Geertz 1977). It is also analytic in a social science research sense and attempts, through qualitative and quantitative analysis of the data, to establish patterns of association of factors involved in illness careers and so to test hypotheses. The study results in discovery and synthesis of a health belief model which serves to explain some elements of patient clinic attendance behaviour in the context of their illness careers and social relationships.

Research interpretation: The personal involvement of the researcher in Nepal and the Leprosy Control Programme

Prior to undertaking this research I had completed 18 years of work in Nepal over a period of 21 years. In the first four years, after an initial period of intensive language study and orientation as a Nurse Educator, I conducted training programmes for female hospital staff, relieved as a nurse in remote village clinics, and taught health and hygiene in high schools in Pokhara.

From 1976 to 1978 and again from 1980 to 1982 I was one of the staff of the new and rapidly expanding Leprosy Control Programme (LCP) administered by the International Nepal Fellowship (INF). During that time I had special responsibility for planning across the project as a whole, for training and health education. A year out (1979) spent at the University of California, Berkeley, undertaking a Masters programme majoring in Health Education at the School of Public Health enabled me to focus on the planning of a comprehensive health education programme for the LCP. During the following three years in Nepal this was largely implemented, being integrated into the LCP.

The responsibility for the training programme provided an opportunity to develop four levels of curricula and for training of Nepali trainers. Along with this the running of the training programmes provided an opportunity to periodically meet, talk with and listen to leprosy field workers. Thus an indirect monitoring of field results and problems was conducted and approaches to the field work were modified subsequently through my planning role across the whole of the LCP. This planning role also involved participation, with other personnel, in the management and administration of the LCP.

During this period the ground work for this present research was laid through a questionnaire interview survey conducted in one district prior to the LCP setting up leprosy case-finding and care services for the first time.

Implications for this study of the author's previous involvement in the field: Avoidance of bias

Miles and Huberman (1984:232-234) deal with the avoidance of biases resulting from the researcher presence in the study setting and the effect of the setting on the researcher. These are discussed here and in the the next chapter on methods in the section dealing with triangulation.

Advantages and researcher effect on the setting

Considerable advantage was experienced through having previously acquired knowledge of the culture and people of Nepal and facility in speaking, reading and writing the Nepali language. Without access to language, access to cultural conceptual frameworks is impossible. Familiarity with the aims, systems, procedures and geographic spread of the LCP was an essential advantage, as were the detailed knowledge of leprosy, both theoretical and clinical, and the social problems encountered by patients in those years.

The fact that the majority of the staff of the hospital and the field of the LCP at one time or another had been my students, was advantageous to my obtaining ready entry to the institution, its departments and access to files and records. It could however have worked against the project a little too, as is discussed below. The helpful, eager co-operation and ongoing interest of the record keepers, clinic receptionists and health workers in the research project were a great boon. This facility was extended by the INF as a whole as well, by the ready provision of housing, visa, administrative backing and transportation. It was an advantage to be familiar with the scene during negotiations with INF for the services of the best experienced Nepali health professional as full-time assistant for the research. The non-judgmental stance we adopted yielded time to consider the LCP dispassionately. Also the valuable experience of frequently being taught by my Nepali research assistant was immeasurable. She was able to be frank, to correct misinterpretations and to add considerably to my understanding of the cultural meaning behind words and events and I am indebted to her for these insights.

Having had a long-standing association with health work in Nepal was also an advantage when it came to relating to government officials in Kathmandu. Contact was, however, not vigorously pursued because the project's early months were overshadowed by political events of great importance. The revolution of 1990 and Nepal's change from absolute monarchy to multi-party constitutional monarchy took place at the same time as the research data gathering. The main contact person in Kathmandu was the Professor of Community Health, also a human rights spokesman. During the revolution he was placed under house arrest but later became Minister of Health in the new and very busy interim government of Nepal.

Being known internationally for my association with leprosy control and training in Nepal was of assistance when funds were sought for travel and the field research. Both The Leprosy Mission International and the American Leprosy Missions provided funds, which the author acknowledges with grateful thanks.

Disadvantages and effects of the setting on the researcher

Some disadvantages of being involved previously are also identifiable. First of all, the fact of personal involvement and of having invested considerable personal effort into the establishment of the LCP, its *modus operandi* and philosophy, leaves one with knowledge but also with biases and opinions about what and how things should be done in a medical sense. This was acknowledged from the beginning of the research project and particular effort made to adopt a non-judgemental, unobtrusive approach to observing and recording events and conversations in an open-minded way, consciously looking and listening to what was actually said and done, rather than interpreting their meaning immediately.

As mentioned above, a further disadvantage was that many of the LCP and hospital staff had previously been my students and would understandably offer replies to questions in forms they thought I would like to hear. Again, having been aware from the beginning, of this likelihood of their reluctance to give real personal opinions if they were thought to be potentially unacceptable to

the "old teacher", an approach to observational visits was adopted which was designed to be as non-threatening and non-judgemental as possible. The approach was two-pronged - firstly to establish a regular presence and secondly to adopt a particular stance. It became routine to make repeated visits to the various departments of the hospital in an unassuming, quiet way so that the staff's work was not interrupted. After some weeks the coming and going of the researchers seemed to be little noticed or remarked upon. The stance adopted was to observe without comment, correction or in any way interfering with the processes or decisions which were being made. Thus passive participant observation (Spradley 1980:59) was undertaken.

Having established presence and adopted this bland, non-critical stance to observing, I was privy to scenes which some of the staff may have previously concealed from their teacher. This was particularly so in the clinic, where the reception by the health workers of patients who came back late for their treatment was less civil than the teacher would have desired.

A third specific disadvantage of having been in Nepal and worked in Nepali for so long was a tendency to assume one already knew and understood conversations and actions observed (indeed my English uses Nepali syntax at times). The tendency to assume one already knew was counteracted by a deliberate questioning, and conscious suspension of judgement. One particular incident, detailed in a case study in the Appendix, served to remind one that one's judgement could be very wrong. Daily discussions with the research assistant were very enlightening and one's knowledge and appreciation of the language and its cultural undergirding were greatly enhanced throughout the study period.

Ethical considerations in action research

Having adopted a non-interfering stance there were two occasions during the period of observation (eight months) when a situation witnessed by the researchers was judged worthy of comment or interference. On both occasions the medical treatment prescribed for the patient concerned was inadequate or incorrect and would have seriously affected their condition or the outcome of the

treatment. On both occasions the interference was done in an indirect way which did not criticise staff. On both occasions the result was positive for the patient concerned. The ethical principles of anthropological professional responsibility (Spradley 1980:20-25) guided the work as a whole as well as these choices with safeguarding the informants' rights, interests, confidentiality and sensibilities being paramount. The role of the researcher in providing valuable feedback to interested parties as the study progressed was considered although formative programme evaluation was not built into the study in this way - but rather as an outcome after the research conclusion

Some unexpected outcomes

The research project generated some unexpected positive effects as well. Even though the research project was not envisaged as formative programme evaluation during the course of the year I was invited to take part in a Health Education seminar for the INF, was invited to present verbal and written progress reports which were discussed with the INF council responsible for medical work, and was repeatedly sought out personally by INF field staff in other projects for discussion of their work and problems. The Nepali research assistant and I were invited to give two one-day seminars on health education for all the Green Pastures Hospital and LCP staff. The study culminated for me with the doctor in charge of INF medical work remarking that having observed the conduct of the project during the year, she was now convinced that social research was a valid occupation for INF personnel.

Part 3: THE RESEARCH SETTING - THE HEALTH EDUCATIONAL PROGRAMME OF THE LCP IN NEPAL AND ITS ASSUMPTIONS

The educational programme of the LCP in Nepal set out to change people's understanding of leprosy, assuming that through such change public attitudes to leprosy and patient compliance with treatment would improve. Consequently, on a broad canvas, this study looks at meanings of leprosy in Nepal as part of a social and cultural construct of reality.

Social reality means the world of human interactions and

relationships, going on within a system of cultural rules, in the context of socially or culturally understood meanings and culturally defined acceptable behaviour (Kleinman 1980:34-35). These understandings are difficult to pin-point and to structure when seen from outside that culture, so that heuristic devices have to be adopted in explanation.

Therefore as mentioned in Chapter 2, in order to give shape to the beliefs and experiences of patients, the concepts of explanatory models of illness (EM) and patient illness careers are used. Explanatory models are said to be the "...main vehicle for the clinical construction of reality..." and reveal the cultural background which produces such clinical reality. Specifically, "Explanatory Models are the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman 1980:105). A Sickness (or Illness) Career is the series of changes of role and status of a person passing from wellness to illness and beyond (Roth, 1963; Twaddle and Hessler, 1977:96-136).

In order to give the study focus, the problem of patient compliance is chosen as a springboard, although findings are not restricted to this category of social and medical phenomenon alone. It is important for two reasons. Firstly, patient compliance improvement was an aim of the health education programme in Nepal and secondly, it continues to be of concern to leprosy control planners (WHO, 1988). For the purposes of the study, compliance is taken to mean patient attendance at clinic to obtain their treatment, and as a "symbol" of other sorts of behaviours and beliefs.

In the LCP health education programme it was assumed that leprosy patients with a scientifically sound understanding of their condition would be more compliant. This assumption can be stated as follows: "...compliance (is)...directly related to the degree of cognitive disparity between patient and practitioner EMs..." (Kleinman 1980:114). This assumption is tested in the research and forms the basis for the study hypotheses.

Study propositions and hypotheses

Just as the cohort-study of compliance provides the springboard to deeper socio-cultural exploration of the context of compliance behaviour in Nepal, so the exploration of the before stated assumption leads into further and deeper investigation of leprosy in Nepal. The study proposed to examine two general propositions.

First - that a relationship exists between patient compliance in terms of the above definition and disparities of explanation of leprosy held by patients and their carers.

Second - that the social meaning of leprosy impacts on patient compliance.

Five hypotheses are suggested from these propositions.

1. A relationship exists between compliance, expressed in clinic attendance, and cultural definitions of sickness and health.
2. Socio-cultural as well as medical meanings of leprosy in the context of Nepali beliefs impact on patient compliance and other aspects of patient behaviour.
3. Cultural concepts of "disease" and "sickness" are reflected in patterns of community social sanction such as social separation of Nepali leprosy patients, and these also impact on patterns of compliance and noncompliance.
4. As well as notions of medical cure, the concept of social health and 'cure' of leprosy in Nepal, as expressed in social integration and re-integration in society, are reflected in patient careers and compliance problems.
5. Ethnomedical and cultural considerations must be taken into account in a health education programme if patient compliance and 'social' as well as 'medical' cure are to be achieved.

In order to explore these propositions and hypotheses the study first examines and then compares explanations of leprosy given by

community members, patients and health workers (Chapter 8). This is followed by an analysis of the cross-cultural context; the health care delivery system, the wider community beliefs and sanctions and patients responses in these (Chapter 10). The impact and meanings of leprosy are related to patient actual clinic attendance and compliance profiles. A documentation of patient illness careers which illustrate the impact of leprosy on their physical, psychological and social conditions is presented (Chapter 11).

This exploration resulted in the uncovering of significant socio-cultural conventions operating in Nepal village society which cut across 'western' medical conventions. Through consideration of these the role of the leprosy patient in the community and in particular their compliance behaviour is better understood. Implications are drawn for the planning of health education programmes and structuring of health care delivery services. (Chapter 12)

CHAPTER 5: PROCESS FOLLOWED AND METHODS USED IN THE STUDY

Introduction

This study as a whole has utilised a combination of quantitative and qualitative methods including those from epidemiology, but primarily from sociology and medical anthropology. The phenomenology approach dominates in its particular discovery of new insights into Nepali socio-cultural phenomena which constrain patient behaviour and relate to patient compliance.

This new understanding was gained through an examination of the cultural context including community expectations of leprosy, the clinical setting in which care was delivered and in which patient and health workers interrelated. Against these were placed the explanations and expectations of health workers and patients along with their experiences. The construction of patient illness career patterns followed a period of intense comparative analysis which revealed the socio-cultural phenomena constraining patient compliance behaviour in a multi-dimensional and multi-layered picture.

This chapter sets out to describe how the study was conducted. Part 1 gives a brief outline of the process followed and types of data sought in relation to the two main research propositions. This is followed by an outline of the seven main types of data gathering each of which is described briefly. In Part 2 the methods used in the research are presented in terms of methods of data collection, survey instruments, timeline of stages of the research, strategies used to ensure data reliability and validity and methods of analysis. This included use of a comparative matrix 'grid' in discovery of new knowledge relating to compliance. The following chapters then set out the findings.

The methods used and the process followed in this research allowed for various layers of social meaning to come together and make sense as a coherent whole. The interrelating of levels of social reality and meaning - from societal systems associated with medicine, health care delivery, clinic attendance, patient understanding of disease and "cure", and patient illness careers

- with patterns of culture and values - builds up the comprehensive and coherent whole picture within which it becomes more possible to comprehend patient compliance behaviour.

Part 1: RESEARCH METHODS USED IN THE EXAMINATION OF THE RESEARCH PROPOSITIONS

The first study proposition examines an assumption commonly made by those from the helping professions as they address the problem of compliance through patient education. The proposition, that a relationship exists between patient compliance and disparities of explanation held by health workers and the patients themselves, was investigated using the following research methods:

1. Compliant and non-compliant categories of patients were identified from the hospital out-patient records through a historic cohort study of compliance, and when previously non-compliant patients returned to the clinic for further treatment.
2. Leprosy patient explanations were extracted from transcriptions of in-depth tape-recorded interviews held with all categories of patients, some conducted at the clinic and others at the homes of non-compliant patients.
3. Health worker explanations were obtained from self-administered questionnaires and from observation of clinic encounters between health worker and patient.
4. Two questions were then asked.
 - a. Do explanations given by various categories of patients differ from those of the health workers?
 - b. Do the explanations of the different categories of patients differ from one another?

The second study proposition, that the social meaning of leprosy impacts on patient compliance, led to an in-depth investigation of the social meaning of leprosy. That was undertaken as follows:

1. Various categories of compliant and non-compliant patients were identified through the hospital records and their attendance or not at the clinic, as described above.
2. A picture of the social meaning of leprosy was built up from various sources and by various means.
 - a. Community explanations of expectations of leprosy were obtained through a survey questionnaire.
 - b. Patient interview transcriptions yielded insights into patients' experiences and perceptions of their condition.
 - c. The dictionary and common meanings of the various Nepali words used for leprosy were examined.
 - d. The law of Nepal, reflecting as it does socio-cultural requirements and sanctions, was examined for mention and regulations placed on people with leprosy.
 - e. A major religious tale mentioning leprosy was obtained after it had been mentioned in a patient interview.
 - f. Provisions for treatment of leprosy found in both Tibetan and Ayurvedic medical literature were examined.
 - g. Case studies of what actually happened to some leprosy patients were gathered.
3. An exploration of relationships between patient compliance and many aspects of the social meaning of leprosy was undertaken through a comparative process using matrix comparative 'grids' mentioned before, within which different elements of data were cross related.

SEVEN MAJOR AREAS OF ENQUIRY

There were seven major areas of enquiry which yielded interlocking layers of data, resulting from the use of qualitative and quantitative methods.

The first was an examination of patient records for evidence of compliance and non compliance, a cohort study. This formed a background quantitative and sampling frame.

Second - a descriptive and documentary study was made of traditional and western medicine in Nepal.

Third - Information on community knowledge and expectations of

leprosy was gathered through interviews.

Fourth - an in-depth exploration of leprosy patient explanations and experiences was conducted through interview.

Fifth - The explanations of health workers, expatriate and local, their congruity and incongruity in relation to perceived roles, were gathered.

Sixth - A participant observation (anthropological) study was made by the researcher of health service delivery, with health worker and patient responses in the clinical setting.

Seventh and finally, was a documentation of further background including illustrative patient case studies.

These are described briefly in turn in this part.

1. Examination and analysis of patient records for evidence of compliance and non compliance - A quantitative study: Cohort study of clinic attendance

This study provided background quantitative data and a sampling frame for selection of two categories of interview patients. This first major gathering of data was through the cohort study of patient compliance. Hospital out-patient records were used and the Cohort Form (Appendix) developed and used for recording details of each cohort patient's clinic attendance and other factors listed. Quantitative and objective data were thus recorded and analysed using a computer programme called EPIINFO. (Computer programme provided by the Centre for Disease Control Atlanta, GA USA.)

2. A descriptive and documentary study of traditional and western medicine in Nepal including the role of traditional healers and differing curative practices

The second major gathering of information for this study was a documentation of the medical system(s) found in Nepal. A special review of the literature was undertaken in order to build up a background picture of Nepal's complex medical system, as described from field observations by anthropologists over the past twenty years or so. The notions of causation or origin of illness, and the kinds of practitioners and curing practices

readily available to the majority of people in Nepal are set out in Chapter 7. It is clear from the information obtained through patient interviews in 1990 that the people with leprosy who are included in this study hold views reflective of the general medical system of Nepal and sought help from a range of practitioners again reflective of those in the general description in Chapter 7. It appears that the medical system of Nepal, while being complex and evolving, is still of the same basic structure as is described by the anthropologists quoted.

3. Community questionnaire survey of reactions to and explanations of leprosy

This survey gave the cultural context to the patient study. This third major gathering of data in the study was from community knowledge and expectations of leprosy patients. This was gained through the use of a researcher-administered questionnaire including some structured, some open-ended questions and vignettes. This was conducted as a separate study and built on a study previously conducted in the same area in 1980.

The community survey which was conducted in 1980 in the District of Nawal Parasi provided the cultural background and became a springboard for this field research. A repeat of the Nawal Parasi community survey provides a picture of present-day community expectations of leprosy. The same interviewer, questionnaire and sampling areas used in 1980 were used in 1990. Results from 160 responses from four areas are discussed in Chapter 7.

Background to community survey

In 1974-5, in cooperation with HMG/N the INF began to develop leprosy control services in the Western and Mid-Western regions of Nepal. District by district case-finding, treatment and follow-up services based on Basic Health Services health posts were established. Case-finding was initially through mass population surveys. However, when it came to case-holding and regular treatment, this method was found to be less effective than having patients initially volunteer for examination.

Patients who had volunteered were found subsequently to be much more regular on treatment than those who had been found by survey. Consequently the case-finding methodology was changed. Health education of the public to stimulate self-presentation and quality care became the backbone of the programme. When Nawal Parasi's turn came in 1980 for being added to the Leprosy Control services network this new policy was already in place.

Immediately before the introduction of these services an epidemiological random sample survey (ERSS) was conducted to try to establish a base-line leprosy prevalence. (This was part of a wider survey which included two other districts.) It was decided to precede the ERSS with a survey of community knowledge and attitudes to leprosy and to use this as a basis for formulating appropriate health education messages as well as a base-line for subsequent evaluation. The data from this survey are available for comparison with the data obtained from the 1990 re-survey of the same area. A detailed comparative report is beyond the scope of this thesis. For this present work, the Nawal Parasi survey data are used to establish the current community attitudes and expectations so as to give the explanations and experiences of leprosy patients a real-life location in the context of Nepal in 1990. The research assistant and a companion used the questionnaire (Appendix) to elicit the data.

Analytical comments about the community survey

In 1980 the total population of the wards sampled was 5413. An average of 46.8 responses were obtained from each, giving an average of an 8.6% sample. In 1990 the population was 4345; 40 responses were obtained from each ward, giving a sample of 7.4%. The 40 repondents were 10 male and 10 female below 30 years, and 10 male and 10 female 30 and over. In each sex and age group people were selected to represent the proportion of their ethnic group in that village population. Instead of obtaining responses to make up the same percentage sample, this survey asked for the same number of responses from each place for reasons of brevity and because this kind of data is not equated with, for example, counting incidences or prevalence of an illness, rather it aims to gain *a picture of the kind and range of beliefs and opinions*

present in the community. The ethnicity of the interviewees reflects their approximate proportions in each place surveyed.

Attempts to ascertain beliefs and attitudes by means of a questionnaire can only be said to give a general idea. One could adopt the methodology of opinion polsters if Nepal was a fairly homogeneous society. Nepal, however, holds a fascinating mosaic of ethnic, language, religious, education and economic groupings, so differences may be expected in beliefs and practices.

In the ten years since the Health Education Programme was launched in Nawal Parasi, the people there have been exposed to many other factors which may have favoured changes in their knowledge and attitudes, for example, considerable in-migration, increases in education and literacy, leprosy advertisement spots broadcast on Radio Nepal, regular treatment and cure of leprosy patients in the area (in 1988/98 alone 74 leprosy patients were released from MDT in Nawal Parasi, while 82 new patients were added and all together there were 386 patients taking regular treatment). Fluctuating economic and political conditions with the recent advent of freedoms, are other recent influences.

The study, therefore, does not attempt to attribute any detected changes to the Health Education Programme itself, rather would suggest that it did contribute to changes, and when looking to the future needs to look closely at currently-held community beliefs and practices.

4. In-depth interviews with a sample of leprosy patients exhibiting a range of compliant and non compliant behaviours to investigate and construct patient illness careers and patients' cultural, social and psychological responses to leprosy:

A qualitative study

The fourth major gathering of data was through transcriptions from in-depth tape-recorded patient interviews. This constitutes the central ethnographic work of this thesis and deals with interview material recorded from 40 leprosy patients in Nepal in 1990 and 1991. Thirty-four interviews make up the main study and

the others were used for background and illustrative case study material.

Half of the patients included in this, the main study, were chosen from the historic cohort of leprosy patients of Green Pastures Hospital. The other half were enrolled in the study as they attended the clinic for the first time or as they returned to the clinic for treatment after a long absence.

Patients interviewed for this main study were categorised as follows:

- a. Regular cohort patients (12).
- b. Newly diagnosed patients (12).
- c. Defaulting cohort patients (10 followed-up - 5 interviewed).
- d. Returned previously defaulting non-cohort patients (5).

This last category constituted a follow-up study of a selection of ten defaulting (OC) patients from the cohort. They were visited at home and provided a further focus on the main players, the people with leprosy. Of the 26 GP cohort patients who were listed as defaulters ten were selected to follow up by home visit. Those patients were chosen who lived in nearby districts accessible by road or within one day's walk of the road.

This defaulter follow-up study had limitations

Ideally it would have been desirable to follow all 26 of the defaulting, or out-of-control (OC) cohort patients. However, limited time and finances confined the study to one month's work for two persons.

The defaulter follow-up study adds strength to the research. Both the choice of a cohort design for patient selection, and inclusion of patients who did not return to the clinic, are features of this study. Vadher and Lalljee (1992) discussed in their review of compliance studies. They remarked that it is "... the systematic loss to analysis of the least compliant patients ... which ... invalidates the conclusions of a large number of compliance-related investigations in leprosy"

(1992:603). The inclusion of defaulter patients in this research gives a broader perspective than is found in most.

The interviews conducted with 32 patients are used in the in-depth exploration of explanations and experiences of leprosy and construction of illness careers. The analysis of these interviews contributed to material found in Chapters 8, 9 and 11.

5. A questionnaire survey of health worker explanations and expectations of leprosy - expatriate and local responses - their congruity and incongruity, in relation to perceived roles

The fifth major gathering of data consisted of a survey of health worker explanations and expectations of patients at clinics.

All expatriate and most Nepali staff from all departments at Green Pastures completed a staff questionnaire in writing either in Nepali or English (see Appendix). This questionnaire included questions relating to explanatory models as well as others relating to health education and understanding of patient problems. Analysis was carried out by listing the responses to key questions on large sheets to create a combined picture of notions of leprosy, meanings and expectations of patients. These are reported in Chapter 10.

6. Participant observation (anthropological) study by the researcher of health services delivery, health worker and patient responses in a clinic setting

Patient - health worker interactions were observed repeatedly and in a manner in which the presence of the observer was at times so routine that it was ignored. The processes for dealing with patients at the hospital were thoroughly investigated. This included the process required of new patients at GP as well as the process followed when patients were late and the action taken on their return. Records of observations were kept in a comprehensive field diary. Some of the observations of these encounters are reported in a case study in the Appendix. Other results appear in Chapter 10.

7. Documentation of rich contextual and illustrative material, including data from interviews and case studies

The seventh major gathering of data in the study consisted of a documentation of various background aspects which filled out the picture of leprosy in Nepal. Examples of contextual materials from interviews and case studies include:

Additional insight was gained from following various of the topics or themes brought up by patients in their interviews and included:

- a) Jhakris. Traditional healers have been used by a large number of the patients interviewed. Two ex-Jhakris were interviewed about their practices and expectations, and other studies obtained.
- b) Hindu Scriptures mentioning leprosy. In the Swasthani Bratkotha story book a Queen became a leper when she dishonoured prasad (offering to the god) and was cleansed when she did the necessary pujas (religious ceremony). This has been translated and appears in the Appendix.
- c) Case Studies
 - i) A regular patient who in spite of 100% compliance and expert medical attention has become progressively worse physically.
 - ii) Two members of the same family (father and son) reported as new patients on the same day. A younger son/brother had had leprosy and had died at GP some weeks prior to our interview.
 - iii) A lady brought her daughter. It transpired that among her relatives leprosy had been present in three and probably four generations.
 - iv) The "animal boy" diagnosed in about 1986, a terai boy of 12 to 14 years who had been living with the domestic animals for a number of years, had finished treatment but was badly deformed. He is not allowed into his home.
 - v) The "jungle lady" spent 18 years (1972-1990) separated from her family living in a cave cooking her own food and looking after the family animals. She was restrained from suicide and sent to Surkhet and hence to GP. She has gross

deformities.

- vi) A recently-diagnosed (1990, seven months prior to interview) patient whose villagers and wife have told him to 'go away and not come back until he is better'. He has no means of livelihood because the people upon whom he depends for work will not give him any. He has no deformity.
- vii) A leprosy asylum: the inside story of Malunga. A patient who had been an inmate of the HMG/N Leprosy Asylum since before the days treatment was available to inmates, and who still stays there. He has stories of the early days and his own way of classifying leprosy.
- d) Previous and current mention of leprosy in the Law of Nepal
Information was obtained and copies of the mention of leprosy by its various Nepali names reviewed. This is reported in Chapter 8.
- e) After observing symptoms of depression (defined biomedically) in many of the interview patients it was decided to administer a standard WHO 25-question screening questionnaire for psychiatric illness to the interview patients - a self reporting questionnaire (SRQ see Appendix) with findings in Chapter 11.

Part 2: DESCRIPTION OF METHODS USED IN PRIMARY DATA GATHERING

In this part the methods used in the research are presented in terms of:

1. Methods of data collection
2. Survey instruments
3. Timeline of stages of the field research
4. Strategies used to ensure data reliability and validity
5. Methods of analysis which included use of a comparative matrix 'grid' in discovery of new knowledge relating to compliance.

1. Methods of data collection

a) The quantitative cohort study

This forms a background to the qualitative work. The cohort consisted of all patients registered as *new patients* at the Green Pastures Leprosy Hospital in the twelve months between 2043/8/1

and 2044/7/last day [approximately 16th November 1986 to approximately 15th November 1987, the Nepali Calender being a lunar one with a variable number of days per month from year to year). The cohort was chosen so that the normal treatment period for all the patients would be concluded by the end of the time available to the researcher, 2047/7/end (mid-November 1990). The study cohort patients were due to complete 36 months' treatment between 2046/8/1 and 2047/7/end (mid-November 1989 and mid-November 1990). The progress of this cohort was followed for the duration of their required therapy (three years). The World Health Organisation (WHO 1988) standard requirement for treatment of leprosy patients with multi-bacillary leprosy (MB) is that 24 monthly doses be taken within 36 months. This is regarded as adequate therapy and therefore the minimum requirement for compliance.

In the cohort study forms were filled in at the beginning of the study, updated at the end of the first field period and again updated during the last field period. Information on patient clinic attendance and medical progress contained in them covered a period from three to four years. The information and analysis were used both to identify various categories of patients for interview in the study as well as to attempt to identify factors common to non-compliant patients. The results of this retrospective examination of compliance behaviour and factors associated with it in 154 patients are reported in Chapter 6.

b) Qualitative data gathering and ongoing analysis

In the clinic setting qualitative study my approach was one of passive participant observer (Spradley 1980:59). Events and conversations were observed and recorded as they occurred. There was no interfering in the processes or situation observed. Taylor and Bogdan speak of the necessity for social researchers to try to "... see things from the point of view of others ...", to "... capture their process of interpretation ..." and to "... suspend one's own commonsense assumptions to study others commonsense (assumptions) in every day life". What this study sought to find from the interview data was the patient's

- (1) description of various aspects of their world;

- (ii) description of their experiences of various aspects of their world;
- (iii) explanation of how they see, describe and explain their world using "...their own commonsense understanding and abstract rules". (Taylor & Bogdan 1984:11)

Observation and writing of a field note diary, together with transcription and translation of tape-recorded patient interviews constitute the basic data in this study.

Access to the clinical setting was gained with ease, and the author and full-time research assistant established a routine of attending the out-patients clinic, after explaining the purpose and method of observation for the study. The fact that the study was partly focussed on patient knowledge of leprosy and compliance was not revealed to the clinic staff as it was thought that it may bias their behaviour in relation to patients. They were told that the study was of patient beliefs and experiences and that the results would benefit patients in general.

Their regular attendance at clinics and departments gave the researchers ample opportunity to understand the routine 'processing' of patients.

In the patient interview study interviews were conducted after obtaining the patient's full agreement. They were informed that the study was to help the researcher in her studies and that information gathered would be confidential. The interviews are conducted apart from the hospital, the patients being assured that we were not part of the hospital and that the things told to us would not go into the hospital.

c) Patient interviews programme

The interviews were conducted in the open air, in a fairly secluded place, near to but out of sight of the out-patients department (see photograph p.110). They were tape-recorded, usually with the patients being aware of the microphone. Interviews were conducted using the topic guide (see Appendix), and using reflective style. Care was taken to avoid suggesting answers to patients. This meant that care was taken not to

introduce key concepts into the conversation, rather take them up if and when the interviewee used them. For example, the use of the term for "leprosy" was avoided, as was the term for "disease". These were only used as the patient used them and their use explored or probed through reflecting them back to the patient as an open question. The interviewer improved in the use of this method as the study went on, as it was a new method for her. The interviews were greatly facilitated by the skills in building rapport brought to the work by the interview assistant. Interviews were in the Nepali (and in one instance contained Tibetan) language. The author was present at all interviews conducted at the clinic, occasionally inserting questions for clarification. The tapes were transcribed by hand into registers and a duplicate copy filed in individual patient research files into which other comments and information were later inserted. After transcription the interviews were coded using the interview topic list, and photocopied, and 'cut and pasted' into code categories. Translations were done and they were all typed in English. The researcher personally translated some of the interviews but, in the interests of time, obtained skilled translation services for the bulk of them. There were 40 in-depth interviews with 436 pages of Nepali handwritten transcript data.

Interviews were conducted with:

1. *Cohort patients* reporting for treatment during the period of time interviews were being conducted. Interviewing was done on three days in March, seven days in April, three days in May, two days in June and four days in July, one day in August, and September, two days in October along with five home visits in October.-November by another interviewer. All the cohort patients were due to come more than once to the clinic during these months. There was a strong chance of their being included. Thought had been given to doing a random selection, but fear of losing too many led to the decision to enrol those who came on the days interviews were done. Practical considerations were also important. The morning was best for conducting interviews as the interview assistant had to be called from her home and could not come as and when

patients turned up. Other work went on in the meantime, including transcription of tapes, initial and ongoing analysis of the interview data and planning of other aspects of the study.

2. *New patients* who were interviewed on the day of their diagnosis.
3. *Defaulter patients.* The Social and Economic Services Department (SES) agreed that three of their staff could be sent to try to find ten of the 26 cohort patients who had not been to the clinic for more than one year and who lived within a reasonable distance. Interviews were as far as possible conducted in the same way as for other patients. Five out of the ten were met and interviewed personally and the families of the others gave some information.

The research assistant chosen to conduct the defaulter follow-up study segment of this research was a trained and experienced leprosy paramedical worker who had been working in the Social and Economic Services Dept. of Green Pastures for some time. He is a high caste and well educated man. He was accompanied by one of the junior SES Department staff to assist and be his 'friend for the road'. The SES Department Head was most helpful in this selection and in making his staff available for the study.

The research assistant was trained in the interview technique, given the topic list and practised on some patients. He listened to some of the taped interviews and the results were discussed. He proved very good at the technique and grasped the method and purpose of the study very readily.

The interviewer received the following instructions:

1. Go to the patient's home and if possible meet and converse with the patient in such a way that his or her social situation is not jeopardised.
2. Tape an interview using the topic list and reflective style.
3. Do a simple physical examination and complete the standard chart for skin, hands, feet and eyes so that the activity of the disease and the deformity grade can be ascertained.
4. Complete the 20-question SRQ for ascertaining indications of

psychiatric 'caseness'.

5. Keep a field diary from which to write a brief report of each visit.

This follow-up study of defaulter patients took place between 047/6/26 and 047/7/23 (October 12 to November 9 1990). The research assistant and companion travelled by bus and foot to each of the village homes of the patients. He succeeded in meeting six of the ten patients. He met family or neighbours of the others. Five patients agreed to a tape-recorded interview; one 'ran away' after an angry outburst.

An unscheduled return to Pokhara was necessary after the seventh visit because the tape recorder was "lost" (see notes on Interview No 39). The research assistant took his own tape recorder to do the last interviews but, as it was old, the quality of the recording was poor. A transcript was not possible so a summary was done in consultation with the research assistant (Interview No. 41). (Both interviews are in Appendix B.)

Even after all this effort the research assistant reported "It was possible to meet only six of the ten patients at their homes. They were Sri. Pariyar, Ali, Sunar, Sharma, Magar and Damai. One of these men refused an interview so the in-depth interview data available for analysis was from five patients. Other data gathered included information about the other five patients given by their families and/or village neighbours.

The report of this study found in Appendix B was compiled using the different material available about each patient. These included:

- a) The translation of the transcribed interview tape (and the Nepali transcription).
- b) Notes on conversations with family or neighbours made by the research assistant (in Nepali).
- c) His report (in Nepali).
- d) Completed SRQ results (see below).
- e) Physical examination charts.
- f) Hospital out-patients card information as copied on to the

Cohort Form I.

Appendix B also includes the summary report of the research assistant which he titled "Facts from the Field" a in loose translation.

2. Survey instruments designed and used.

The form developed for recording information about the patient cohort (in English) was based on two standard record forms used in the INF LCP, namely the clinical record kept at Green Pastures Hospital and the form used to record patient information for the mobile clinic.

This cohort study examined factors of disease, therapy progress, socio-economic and other factors. These were related to the record of clinic attendance. Along with these, which are factors commonly found in compliance studies others of possible significance were added. (See appendix)

The questionnaire from the 1980 community survey was re-used in this study in 1990. The questions asked were all the same and the original format was retained except in the last small section where a new kind of question was introduced. The purpose was to attempt to elicit public opinion on what should or would happen to leprosy patients under certain circumstances. They replaced the 1980 questions but were seeking the same kind of information. Instead of asking direct questions about social dealings "vignettes" which asked the same questions in an oblique way were used. These were stories setting out situations about which the people were asked what could or should happen now? What would they do now? And so on. (See appendix)

The interviewers reported having trouble administering this part of the questionnaire. The problem related mostly to language but also to the lack of experience of the respondents in making the kind of decision required by the question. However these stories yielded useful insights into people's stated beliefs about what they expect others to do. The questionnaire was pre-tested in Pokhra by the research assistant and minor alterations made.

After the questionnaire was pre-tested and altered slightly the research assistant and companion made a preparatory visit to the district officials in Parasi and then each sampling section was visited and the survey conducted. The survey took between two and three days in each place, a total of 39 days. In each place the interviewers obtained the population figures from the village secretary or other knowledgeable leader.

The main instrument, the interview guide for the patient in-depth interviews, was developed and tested over some weeks. Issues of the style of interview (reflective) and meaning of Nepali terms were discussed between the researcher and Nepali colleagues. A major item of work was the *preparation of the Nepali question list* for the patient interviews following the topic list devised combining the concepts of explanatory models and illness careers. The list of Nepali questions went through two revisions after trial and intensive discussion on the purpose of the questions and the meaning and cultural implications of possible alternative Nepali terms to be used. It was important to choose Nepali terms which did not suggest the answer and which were general enough to allow for a breadth of reply which could include folk beliefs and a definition of the problem in the words of the interviewee. It had been noted that key terms used in clinical interviews allowed very narrow replies. The topic guide included in the Appendix was used as the basis for this process. The interviewer practised asking questions in an open ended rather than a suggestive style.

3. Chronology and time line of the field research

A brief chronology of the study

The research (data gathering) was conducted in Nepal from February to December 1990 and October 1991 to February 1992. The process of conducting the research is listed here roughly in the order of events although a number of activities were running concurrently.

Initially the purpose of the research, location, access, resources, provision of staff, funding arrangements were all

established through discussion and agreement with responsible officers of the International Nepal Fellowship, the Leprosy Control Programme and Green Pastures Leprosy Hospital in Pokhara. The cohort patients were enrolled from the clinic records and initial analysis done.

The patient interview guide was formulated. Tape-recorded interviews began with cohort patients when they attended the clinic. The process of analysis began at the same time.

Debriefing of interviewer and researchers was necessary repeatedly as the interview data, the stories of the patients, touched us emotionally.

The psychological well-being of the interviewees was assessed using a self reporting questionnaire obtained from mental health specialists in Kathmandu.

Participant observation study of the clinic setting was in progress during the whole period of the field work.

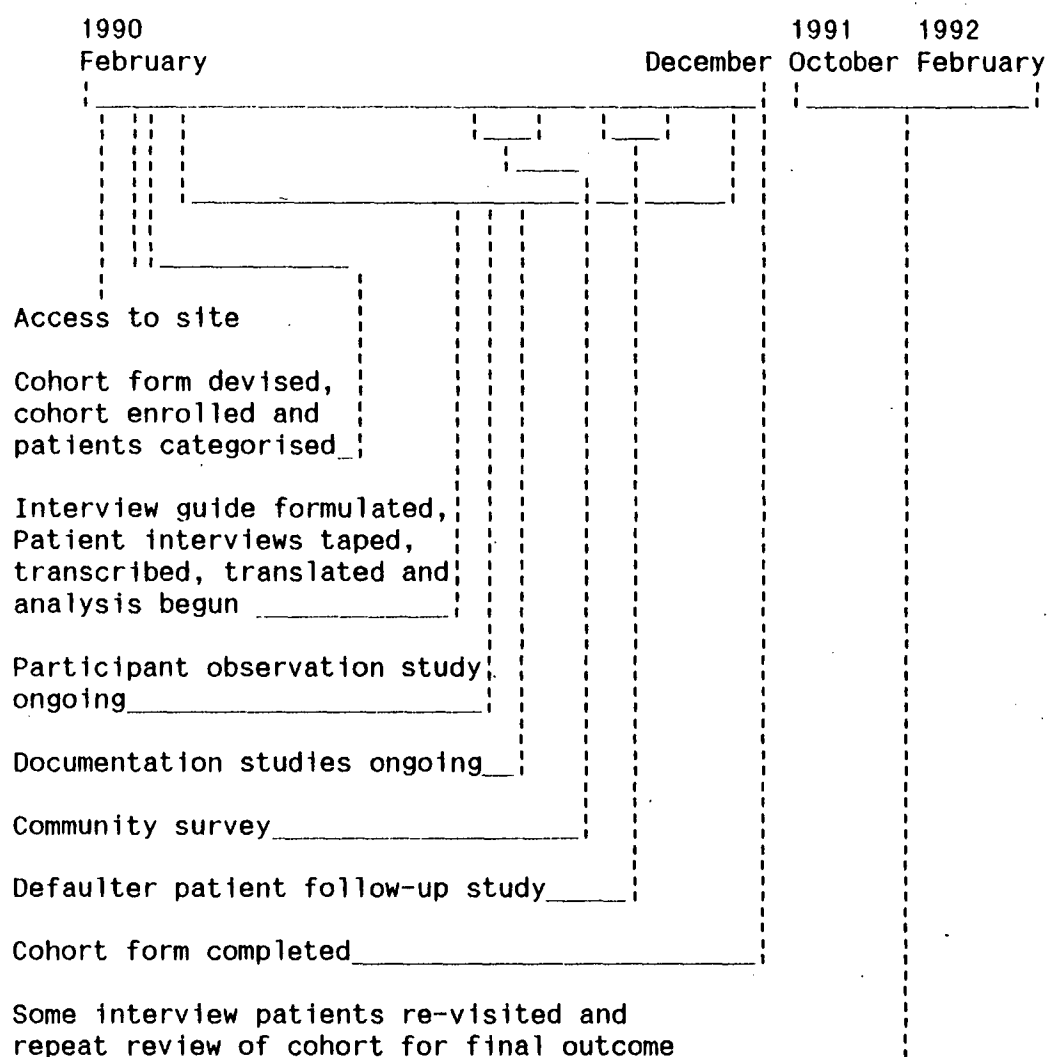
A repeat of the 1980 community survey in Nawal Parasi was negotiated with the Social and Economic Services (SES) Department of the LCP. The questionnaire was revised and tested, the researcher instructed on the protocol, the programme devised, supplies and necessary written authority obtained.

After identification of defaulting patients from the cohort, the follow-up survey was arranged again with the co-operation of the Socio-Economic Services Department.

The last activity of 1990 was to complete the 154 cohort forms from the patient clinic cards, noting specifically their actual clinic attendance record up to that time.

During the visit to Nepal in 1991-92 the author was able to repeat this survey of cohort patient cards, talk with some of the interview patients, and staff and visit one rural patient.

Time line of data gathering field work in Nepal



4. Strategies to ensure reliability and validity of data

The implications of the researcher's personal involvement in the field, as discussed in the previous chapter, are of particular relevance in relation to ensuring reliability and validity of data in this study. The researcher's long and intense personal involvement in Nepal and the Leprosy Control Programme implied a specific strength for the study because of special insights and understandings thus gained, but also brought the danger of bias perhaps because of over-identification with particular groups or favouring certain interpretations.

Avoiding bias

Testing and confirming findings including avoiding bias is dealt with by Miles and Huberman (1984:230-243) who suggest that there

are three "archetypal biases" in qualitative research. The researcher may interpret events as "... more patterned or congruent than they really are ...", or may overweigh data from "... articulate ... high-status informants and underrepresent data from ... less articulate ... ones." or may be "... coopted into the perceptions and explanations of the local informants ..." thus losing his perspective (1984:230).

Being very aware of these potential biases the study was conducted in such a way as to reduce as far as possible the biases stemming from researcher effect on the site and effects of the site on the researcher (1984:233-4).

Miles and Huberman (1984:233) suggest six measures for avoiding bias stemming from the effect of the researcher on the site. Throughout the study these were applied. For example, a competent Nepali research assistant was recruited from the beginning. She was able, among other things, to be attentive to my "... influence on the site and its inhabitants". We stayed a long time at the site, spending some time "... simply hanging around, fitting into the landscape, taking a low profile". The general purpose of the research was made clear to the staff of Green Pastures and to the patients as they agreed to be interviewed. The specific aim of examining patient clinic attendance or compliance in particular was not spelled out because it was reckoned that had that been made explicit the behaviours under study would very likely have been changed for our benefit, particularly those of the staff dealing with patients attending the clinic. The data gathering exercises were kept as unobtrusive as possible so as to intrude on staff and patient time and goodwill as little as possible. Finally, even though the question of patient compliance and understanding it better is an important one for leprosy control it is by no means the greatest or most pressing everyday problem that must be dealt with so the importance of the research was not inflated.

Miles and Huberman (1984:234) also suggest measures for avoiding bias stemming from the effect of the site on the researcher. These measures, one of which is triangulation, were also in place

throughout the data gathering and analysis. For example, the study informants were a broad spread of people closely or more remotely associated with the study site as well as those who had no connection at all. The views of those not connected with the setting helped to keep a broad perspective. The daily discussions between researcher and assistant went on translating "... sentimental or interpersonal thoughts into more theoretical ones". Various "off-site" informants provided background and historical information and helped again to achieve a broad and balanced view of the material. When we sensed we were being misled by informants we explored the reasons carefully, one such instance involved the disappearance of the tape-recorder on a home visit to interview a defaulter patient. This is discussed in the findings chapter. The notes and initial findings were viewed by and discussed with several competent but uninvolved professional researchers during the data gathering period for exposure to other thinking. Even though this research was a multi-dimensional and multi-layered approach the core research question and propositions were kept firmly in mind when following "... alluring leads..." in a grounded research mode.

In these ways, and through triangulation as discussed below, I believe the obvious dangers of personal bias were honestly faced and diminished as far as is humanly possible. The equally obvious advantages of having an intimate and comprehensive knowledge and understanding of the subject, the land and the setting were utilised to the fullest extent in completing this work at a depth some researchers more recently come to a setting would be unlikely to reach in the time.

Triangulation

Triangulation means the "...combination of methods or sources of data in a single study" (Taylor and Bogdan 1984:68). As mentioned above the core of the study, investigating the meaning and impact of leprosy in the lives of people, was approached from a variety of angles. Various sources, such as clinic records, patient interviews, clinic observation, community survey, religious and legal documents, and so on, were used. Health worker explanations are taken from the questionnaires they

completed and refined through further observation and conversations in the clinics. The knowledge of community members comes from the researcher-administered questionnaires as well as from the researchers' reports of their field visits, verified by informal discussions with community members. Patient illness careers are constructed from various sources, interview transcripts, clinical notes, follow-up conversations, verified through questions with associated people. Historic and religious literature was searched for suggested background to the meaning of leprosy in Nepal. This approaching of a concept from many angles and through use of a variety of methods in an attempt to verify the accuracy of information is termed triangulation. As Miles and Huberman put it triangulation is "...precisely how you get to the findings in the first place - by seeing or hearing (or reading) multiple instances of it from different sources, and by squaring the finding with others..." (Miles and Huberman 1984:234). In this study such "cross-verification" (1984:234) was sought for all data gathered as well as being a feature of the study design as a whole.

In summary then the study gathered data from written records, reports, published literature; from tape recorded interviews, transcribed by hand in Nepali and translated into English; from field diary notes of observations and conversations with clinic, hospital staff and patients and from observation during regular repeated non-intrusive presence in the clinic; from notes made while observing and following patients during their progress through the clinic system; from researcher and subject-completed questionnaires and from discussions and reports of village home visits; and from regular intensive discussions with research assistants and other key informers.

5. Methods of analysis - including the construction of the comparative "grid".

In analysis of the patient clinic attendance records several key questions were examined, such as:

What is the actual compliance record of these patients?

What are the characteristics of compliant/non-compliant

patients?

Are there factors associated with compliance and non-compliance?

The data from the cohort forms was entered into the EPIINFO programme for analysis. In general this study followed the results of other such studies in that there were no clear indications of significant factors associated with compliance.

The method of analysis of qualitative research data

A modification of *Grounded Theory* was the style of qualitative analysis used to draw meaning from the mass of interview data in this study. Strauss (1987:xi) comments about grounded theory:

Although its originators and principle users to date are sociologists, it has been found useful by social scientists from other disciplines, as well as researchers in education, public health, social work, and nursing – found useful because it is a general style of doing analysis that does not depend on particular disciplinary perspectives.

During the field work year in Nepal, Taylor and Bogdan (1984) was found to be of practical help. The analysis of data went through certain phases, most of which were ongoing and simultaneous. Taylor and Bogdan (1987:130-140) name four phases of data analysis: First *discovery*, entailing identifying themes and developing concepts and propositions; *coding* follows, in which different categories are developed and data sorted into categories; after this, one's understanding is *refined* along with the code category lists; and finally the data is *discounted* through interpreting them ... assessing their credibility...in the context in which they were collected.

This process was iterative, with the data revisited repeatedly, and concurrent rather than linear or sequential, and it included the following elements given below in more detail:

Discovery

1. Read and re-read your data.
2. Keep track of themes, hunches, interpretations and items.
3. Look for emerging themes.
4. Construct typologies and classification schemes.
5. Develop concepts and theoretical propositions.

6. Read the literature.
7. Develop a story line.

Coding

1. Develop coding categories.
2. Code all the data.
3. Sort the data into coding categories.
4. See what data are left out.
5. Refine the analysis.

Discounting the Data.

1. Solicited or unsolicited.
 2. Observer's influence on the data.
 3. Who was there.
 4. Direct or indirect data.
 5. Sources.
 6. Your assumptions and presuppositions.
- (Taylor and Bogdan, 1984:129-145)

In this study the use of an interview guide provides some preconceived shape to the data. However, these data also threw up other themes, topics and ideas which were noted and looked into later. The patients who talked particularly freely were the ones who introduced other material. Part of the purpose was to read and re-read the data to find themes which in the end formed parts of the suggested new theoretical constructs for understanding the phenomenon being studied. The concept is that the theory is "grounded" in the data.

Analysis of the interview transcripts and translations

The repeated reading and discussion of these data produced:

- a) An understanding of the ways in which leprosy patients explain their condition, the "distance" of their explanations from those of their health workers and the relationship of these "distances" to their compliance behaviour. These are reported in Chapters 8 and 11.
- b) Descriptions of leprosy patients' experiences of leprosy, building up a picture of the illness careers of leprosy patients. These were constructed from interviews and other

records, and these are reported in Chapter 11.

- c) New insights into related factors through a re-visiting of all the interview data, both Nepali transcripts and English translations, to ask questions not implicit in the interview guide construction. These are reported in Chapters 9 and 12.
- d) Comparisons of explanatory models and experiences between various patients. These are reported in Chapter 11.

The use of the comparative 'grid' in this process is discussed below. The process proved very time consuming and intensive. Each interview was so full of information, thoughts and leads to follow up, that the number of interviews needed and were feasible was found to be limited. However, the process uncovered new relationships.

The discovery of patient illness career patterns and relationships to compliance

Explanatory Models and Illness Careers Patterns of various categories of patients are constructed from data gathered by in-depth interviews which were conducted in a reflective style and guided by a topic list. Analysis of this material was by modified Grounded Theory method and a comparative grid, developed for the study.

The Nepali and English transcripts and translation material was subjected to a major re-visit after the initial analyses of all data were completed. This renewed analysis took a different approach in that it looked outside the constructs implicit in the data from the topic list itself and sought relationships previously unexpected. The source of new insights was found to be included in the answers to general questions about the patients' family situations. The process is further described and results reported in Chapters 9 and 11.

Further information on Illness Careers was obtained through follow-up informal interviews with the persons concerned and with third parties.

The Comparative 'Grid'

The comparative grid, developed to search for associations between various factors from patient interviews and other information consisted of a chart, drawn on paper. The development of the instrument came fairly late in the study after a large amount of ethnographic and interview data had been collected and analysed. This process of 'data reduction' as discussed by Miles and Huberman (1984) is the process of selecting, focussing, simplifying and reducing data in the form of words. It "...occurs continuously throughout the life of any qualitatively oriented project...the data-reduction/transforming process continues after field work until a final report is complete" (1984:21).

Various hypotheses relating factors in the patient's social and cultural environment to the patterns of illness careers were emerging in the nature of a grounded theory approach. Further data reduction was needed. A way of testing the relationships between factors and social events, and patient compliance and illness career patterns were sought. The need for a systematic method of relating 'chunks' (Miles and Huberman, 1984:68) of qualitative data in a way which allowed for comparison across cases suggested the use of a matrix, here called a comparative 'grid'.

The way this was constructed was straight forward on the surface but necessitated re-visiting interviews and other primary data and examining in detail the answers to specific questions asked in relation to the 'grid'. This process was like the generation of 'pattern codes' discussed by Miles and Huberman (1984) which "...reduces large amounts of data into a smaller number of analytic units" (1984:68). This was time-consuming and labour-intensive but allowed the researcher to uncover important relationships and processes so far embedded in the data.

Down the left margin of a page factors to be compared were listed, such as patient's demography and disease, and socio-cultural factors such as whether the patient was living with his family, in his village, who knew about his condition and so on.

Information about each patient in turn was listed in columns beside these factors. The chunks of "coded" data then became variables within a pattern of data relationships, and the grid" a way of depicting a data matrix in which correlations, or repeated associations between variables, became easier to perceive. This device allowed an overview of key factors for all interview patients. The importance of factors related to concealment, for example, became clear by this means, and led to the development of the concealment 'grid' and clarifying illness career patterns. Interpretation was naturally aided by the total cultural immersion undertaken in this study.

Concluding remarks

This chapter has set out in some detail the processes followed in exploring the study propositions, the main areas of enquiry and research methods used, along with methods of analysis. Through the iterative process of data gathering, data reduction and data analysis new insights and interpretations have been gained, data relationships discovered and hypotheses generated and tested. Through this process and from these data it is clear that when their expectations and experiences are set in their socio-cultural context, an understanding is gained of the place of compliance in the illness careers of leprosy patients in Nepal.

This understanding was gained through the process detailed above. The cultural context was examined, described and analysed from information gathered by means of a questionnaire survey of Nepali communities. Through interviews, questionnaires and observations the explanations and expectations of health workers and leprosy patients became clear.

The core of the study, in-depth interviews of the patient, provides rich material from which their explanations and experiences of leprosy were extracted and described. This patient interview data, in both Nepali transcript and English translation, was re-visited and new questions were asked of these data. This exercise yielded new understanding of socio-cultural conventions operating in Nepali society in relation to leprosy and compliance.



VILLAGE AND DOMESTIC
LIFE IN NEPAL

A Gurung village
west of Pokhara.
(Nepal 1985:233)



Meal preparation
Pokhara.
(Hyland)



The whole process of
rug making in the
countyard of a
village home in
eastern Nepal.
(Hyland)

CHAPTER 6: RESULTS OF THE COHORT STUDY OF COMPLIANCE WITH CLINIC ATTENDANCE.

A QUANTITATIVE STUDY: COHORT STUDY OF CLINIC ATTENDANCE

This study provides a background to the main body of the thesis, the ethnomedical study. The findings are presented here as a prelude to the socio-cultural exploration of the question of compliance with clinic attendance in the specific setting of the LCP in Pokhara, Nepal.

As mentioned in Chapter 5, the cohort consisted of all patients registered as *new patients* at the Green Pastures Leprosy Hospital in a twelve-month period. The cohort was chosen so that the normal treatment period for all the patients would be concluded by the end of the time available to the researcher. The progress of this cohort was followed for the duration of their required therapy (three years).

This study examined disease factors, therapy progress, socio-economic and other factors. These were related to the record of clinic attendance. Along with these factors which are commonly found in compliance studies, others were added which may have been of significance.

1. An estimation of the cost of attending was made. Calculations indicated that for free treatment it costs patients who attend regularly once per month for the 24 months approximately Rs3,000/- (Rs126/- per month out of average estimated monthly earnings of Rs400/-). For most patients this estimate did not represent actual money spent or lost as most of them were not wage earners, but rather represents lost earning potential or value of labour lost, for instance.

2. Action taken when patients were late for appointments and the results of these actions. It was noticed that some of the patients became defaulters after having been late once. When they came back they were fined and "given a row" and they did not come back again. Other defaulters came initially when they had severe symptoms which required hospitalisation. Once these

symptoms were better the patient did not come again.

All factors were obtained from the patient record cards and recorded on *Cohort Form I. (Appendix)*

Analysis of the Quantitative Data

A computer programme for analysis of epidemiological data, EPIINFO, was used. In general this study followed the results of other such studies in that there were no clear indications of significant factors associated with compliance.

Patient Clinic Attendance.

Several key questions were examined, such as:

What is the actual compliance record of these patients?

What are the characteristics of compliant/non-compliant patients?

Are there factors associated with compliance and non-compliance?

Description of the Cohort

Total Cohort

During the twelve-month period 154 new patients were diagnosed and enrolled for treatment. Among them were 25 with paucibacillary (PB) and 129 with multi-bacillary (MB) leprosy.

During the period after their enrolment 53 were removed from the clinic list through transfer to other centres for treatment.
(6 PB, 47 MB).

There remained 101 patients registered for treatment at the Green Pastures Leprosy Hospital Out Patients clinic. This remaining cohort contain 19 PB, 82 MB.

These results were seen by the end of the study period in 1990:

| | | | | | |
|-----|---|--------|-----------------------------------|---|--------------|
| 101 | - | 7 Died | | - | 1 PB |
| | | | | - | 6 MB |
| | | - | 43 Released from treatment \ | | |
| | | - | 25 Continue treatment | / | - 68 Regular |
| | | - | 26 Defaulted, out-of-control (OC) | | - 26 OC |

Profile of the Total Cohort Before Deduction of Transfers

How representative or different is this cohort from all the new patients registered in the whole of the LCP that year? How does this cohort compare with the total registered patients from the LCP? There is a major difference between this cohort and the total registered patients on the register in any one year.

The total LCP registered patients is made up of two groups of patients. First it does include the new patients registered that year (the study cohort) but not all of them, as some PB patients may have been registered and released from treatment within the said twelve months. It also includes MB patients diagnosed up to three or four years prior to the report who are continuing their treatment. Consequently there is an accumulation of MB cases and some PB patients may not have been included. LCP Annual Reports are used for these comparisons (LCP 1986/87).

In the whole of the LCP a total of 1645 new patients was diagnosed that year. The study cohort of 154 represents about 10% of these. MB proportion was 59%. Positive smears were 26% of patients. Gender ratio was 2.83:1. The gender ratio of the cohort was different from that of all the new patients in LCP (2.58:1 compared with 2.83:1). This means that the proportion of female patients reporting to Green Pastures for diagnosis is slightly higher than the overall. This might reflect the fact that it is probably easier for females to travel to Pokhara for other reasons (thus concealing their real intention) than it would be for them to do the same at health posts.

Classification according to PB-MB type of leprosy was 25 PB and 129 MB leprosy. This is an MB rate of 83.7% compared with that of the LCP total new patients that year (MB 59%), and the overall LCP MB Proportion (also 59%). The difference between the MB proportion found in the study cohort and the rest of LCP may reflect at least two factors, firstly a more conservative classification practice of the health workers at the Green Pastures clinic and secondly, that the patients reporting to Green Pastures Hospital had more complications than those who reported to other clinics where facilities are limited, MB

leprosy being more likely to become complicated. Clinical policies at Green Pastures Hospital are not exactly the same as those of the LCP field work and new practices. For instance an alteration to a practice like classification of PB-MB takes time to percolate through all the field workers and to stabilise. A newly-adopted classification policy would be introduced first at the hospital and communicated to the field workers. After it was noticed that a number of PB patients relapsed after being released from treatment, a more conservative classification policy was introduced (LCP 1986/87:6, 87/88:25).

For the study cohort details of the classification of the type of disease manifesting are given. The Ridley-Jopling classification allocates a place on a spectrum said to be representative of degree of immunological resistance present: Indeterminant (I) meaning that the disease is in such an early stage that it is not yet possible to determine which type will develop; polar Tuberculoid (TT) which is said to resemble tuberculosis of the skin; Borderline Tuberculoid (BT) which has more eruptions than polar tuberculoid but of a similar nature; Borderline Borderline (BB) which is an unstable state and shows eruptions from both sides of the spectrum ; Borderline Lepromatous (BL) which begins to show elements of the full blown leprous picture of swollen nodular lesions on face and body; and the polar Lepromatous (LL) in which the skin is swollen, inflamed and loaded with bacteria and the person's body has little or no resistance to M.leprae); and finally Neural (N) in which only nerve lesions but no skin lesions are present.

There were no indeterminate patients; tuberculoid patients: were four; borderline tuberculoid: 59 (21 PB and 38 MB); borderline borderline: 10; borderline lepromatous: 51; lepromatous: 23; and neural: 7. It is noted that patients classified at the MB end of this spectrum are potentially more at risk from complications than the others. They represented 84% of the initial cohort. They present a greater challenge to health workers, who require a level of clinical expertise for their adequate diagnosis, classification and management higher than that required for routine management of uncomplicated cases.

Comparison of various categories of Cohort patients

| Categories: | Total Cohort | Transferred | Remaining Cohort | treated at GP | | | All LCP |
|-------------------|--------------|-------------|------------------|---------------|----------|----------|---------|
| | All | IT | Died | Rx at GP | Regular | OC | |
| Number: | 154 | 53 | 7 | 94 | 68 | 26 | 1645 |
| Gender: males | 111 | 41 | 4 | 66 | 48 | 18 | |
| females | 43 | 12 | 3 | 28 | 20 | 8 | |
| M:F Ratio (x:1) | 2.58 | 3.41 | 1.33 | 2.35 | 2.4 | 2.25 | 2.83 |
| Type: PB | 25 | 6 | 1 | 18 | 15 | 3 | |
| MB | 129 | 47 | 6 | 76 | 53 | 23 | |
| MB proportion: | 83.7% | 88.6% | 86% | 80.8% | 78% | 88.4% | 59% |
| Smear positive: | 78 (53%) | 31 (60%) | 2 (28%) | 45 (48%) | 32 (47%) | 13 (54%) | |
| Disabled Proptn | 47.4% | 56.6% | 57% | 51.7% | 54% | 23 | 21% |
| Presenting S&S: | | | | | | | |
| - skin patches | 97 (63%) | 32 (60%) | 1 | 64 (68%) | 49 (72%) | 15 (58%) | |
| - nodules | 5 (3%) | 1 | 1 (14%) | 3 | 3 | 0 | |
| - anaesthesia | 72 (47%) | 28 (53%) | 1 | 43 (46%) | 33 (49%) | 10 (40%) | |
| - ulcers | 43 (28%) | 20 (38%) | 3 | 20 (21%) | 12 (17%) | 8 (31%) | |
| - RR | 53 (34%) | 15 (28%) | 3 (43%) | 35 (37%) | 25 (37%) | 10 (40%) | |
| - swelling | 27 (17%) | 13 (25%) | 3 | 21 (22%) | 12 (17%) | 9 (35%) | |
| - paraesthesia | 26 (16%) | 11 (21%) | 1 | 14 (15%) | 12 (17%) | 2 | |
| - paralysis | 25 (16%) | 6 (11%) | 0 | 19 (20%) | 11 | 8 | |
| - ENL | 9 (6%) | 5 (9%) | 1 | 3 (3%) | 1 | 2 | |
| - Nerve pain | 15 (10%) | 4 (8%) | 0 | 11 (12%) | 7 (10%) | 4 (15%) | |
| Other conditions: | 18 (11.6%) | 3 (6%) | 3 (43%) | 10 (10.5%) | 6 (9%) | 4 (15%) | |
| Hospitalised | 54 (35%) | 21 (40%) | 4 (57%) | 29 (31%) | 24 (35%) | 5 (19%) | |
| Steroids given | 40 (26%) | 11 (21%) | 1 | 28 (31%) | 25 (37%) | 3 (12%) | |

In the study cohort those with a positive smear upon diagnosis were 78 or 53%. This left 76 patients who were smear-negative. Of these, 51 were classified as MB and placed on the treatment regimen of 24 months minimum along with the smear-positive patients. Of the LCP new patients, only 26% were smear-positive. This difference may reflect again that the cohort reporting to Green Pastures Hospital is made up of patients with more advanced leprosy. It may also reflect a more thorough and accurate system of smear-taking, reading and reporting at the hospital than in the field. The proportion of patients who had smears taken in the whole of the LCP during this year was 76%. In the study cohort 100% of the 154 patients had smears taken and reported on.

Presenting symptoms and signs

A further indication of the varied and complicated nature of leprosy diagnosis and management requirements is gained from the range of signs and symptoms(S/S) found upon initial physical examination of new patients. (Responses to this section of the form are multiple, that is one patient may have one, two or even three of the S/S on the list, so totals do not add to 154.) Skin patches were found in 97 (63%) patients, nodules in five only

(3%), 26 (17%) had paraesthesia while 72 (47%) had areas of anaesthesia, 15 or 10% spoke of nerve pain, 25 or 16% had some paralysis, some kind of ulcers were found in 43 (28%), nine or 6% of patients presented with established ENL, 27 or 17% had swelling of the hands, feet or face, and 53 or 34% presented with some degree of reversal reaction. Other general medical or psychiatric conditions were diagnosed in 18 patients (12%). Comparative information about presenting signs and symptoms is not available for the LCP total new patients.

Admission to Hospital

Of the 154 new patients seen that year (the study cohort), 54 or 35% were hospitalised some time during the study period and 40 or 26% received at least one course of steroids.

Disability

As to disability, 83 or 55% initially had some disability. Of these 10 were WHO Grade 1, 70 were Grade 2 already and three were Grade 3 and three unknown. The extent of disability (a measure devised by the author for the study) , being the number of body sites involved (hands, feet and eyes), was also recorded for the cohort. Of those with disabilities, 24 (16%) had only one site involved, 24 had two sites, 12 were affected in three, 19 in four, four in five sites and three people were already affected in both hands, both feet and both eyes.

The number of patients who were affected in more than two sites was 38, representing 46% of those disabled or 25% of the whole cohort. By comparison, among all the LCP new patients, disability was not present in 46% of patients. Of the remainder (54% with disability), 57% were Grade 1 and 43% were Grades 2 and 3. In other words the disabled proportion in the study cohort is higher than that for all the LCP new patients. Disability extent is not routinely recorded in the LCP.

Cohort profile: Initial disability

| WHO Grade | 0 | 1 | 2 | 3. | Extent | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|-------------------------------------|-----|----|-----|--------|---------------|----|-----|-----|----|-----|----|--------|
| Number | 68 | 10 | 70 | 3 (3U) | | 68 | 24 | 24 | 12 | 19 | 4 | 3 (3U) |
| Per cent | 44% | 6% | 45% | 2% | | | 16% | 16% | 8% | 12% | 3% | 2% |
| Disabled proportion 47% (Grade 2+3) | | | | | 3 + sites 25% | | | | | | | |
| (3 Unknown) | | | | | | | | | | | | |

Disabled proportion (WHO Grades 2 and 3) for LCP that year

For all patients registered, the disabled proportion was 21%.

In new patients registered in the field the disabled proportion was 16%.

For those registered in referral centres the disabled proportion was 29%.

For all new patients that year in the whole of the LCP both field and referral centres the average disabled proportion was 22%.

(Disability among all the patients on the register at this time was 33% with no disability, 18% with Grade 1 and 21% with Grades 2 and 3. 28% of patients did not have disability assessed.)

The cohort disabled proportion of 47% is high, representing a greater proportion of advanced and complicated cases managed at the hospital than in the field. Upon initial diagnosis these people already had a heavy burden of physical damage due to the disease and complications. Many of them had eventually sought help at the hospital rather than from health posts precisely because of the hospital's extra facilities for dealing with complications. It could be asked, of what significance is this difference between the populations of patients seeking treatment

| Footnote: * Disability Grade as defined by WHO (1970) | | | |
|---|--|---|--|
| Grade | HAND | FOOT | EYE |
| 1 | Insensitive | Insensitive | Redness of conjunctiva Corneal anaesthesia |
| 2 | Ulcers and injuries Mobile claw Slight absorption | Trophic ulcer Claw toes or Foot drop Slight absorption | Lagophthalmos Blurring of vision Inflammation of globe |
| 3 | Wrist drop Fingers clawed with Stiff joints Severe absorption | Contracture Severe absorption | Severe loss of vision Blindness |

from hospitals and from health posts? Does it make a difference to the study of compliance? The question is difficult to answer but it may suffice to say that given that a higher proportion of non-disabled patients tend to default from treatment one could reasonable expect that the referral centre defaulter rate would therefore be lower than that in health posts. It has already been seen in Chapter 3 that the reality is the opposite. It is therefore ventured that it could make the compliance study of the referral centre cohort more pertinent.

Comparison of remaining Cohort with Out-of-Control patients.

| Total per category: | | Continuing Rx | OC |
|--------------------------------|----|----------------------|-----------|
| <hr/> | | | |
| Total patients 101 (died 7) | | | |
| Living patients | 94 | 68 72% | 26 28% |
| <hr/> | | | |
| Gender: males | 66 | 48 73% | 18 27% |
| females | 28 | 20 71% | 8 29% |
| According to type: | | | |
| PB | 18 | 15 83% | 4 17% |
| MB | 76 | 53 70% | 23 30% |
| Smears: Pos. of | 45 | 32 71% | 13 29% |
| Disabled: | 45 | 37 82% | 8 18% |
| Presenting Signs and Symptoms: | | | |
| - skin patches | 64 | 49 77% | 15 23% |
| - anaesthesia | 43 | 33 77% | 10 23% |
| - Reversal Rn. | 35 | 25 71% | 10 29% |
| - swelling | 21 | 12 57% | 9 43% |
| - ulcers | 20 | 12 60% | 8 40% |
| - ENL | 3 | 1 | 2 |
| - nerve pain | 11 | 7 64% | 4 36% |
| Hospitalised: | 29 | 24 83% | 5 17% |
| Given steroids | 28 | 25 89% | 3 11% |

From these figures it is noted that:

1. Fewer PB (17%) patients tend to be OC, and more MB (30%).
2. Fewer patients with patches (23%) were OC. than continued.
3. Fewer with anaesthesia (23%) were OC. than continued.
4. Fewer hospitalised (17%) than non-hospitalised were OC.

5. Fewer patients who received steroids (11%) than those who did not were OC.
6. Fewer initially disabled (18%) than non-disabled were OC.
7. More with swelling (43%) than not swollen were OC.
8. More with ulcers (40%) than with no ulcers were OC.
9. More with ENL were OC (n=2 only).
10. More with nerve pain (30%) than those without were OC.

Comments on these in turn:

1. Because PB patients are only required to take six months treatment they have less time in which to be absent than the MB patients who must take at least 24 months medicines. This may explain some of the difference.
2. Patches are often associated with PB leprosy so the above may apply here too.
3. Anaesthesia and disability are associated because anaesthesia is an indication of nerve damage and may progress to disability. It seems from some of the interview material, that some patients expect these symptoms of anaesthesia to get better. They continue treatment with that hope. Perhaps it is because these people regard their condition as serious that they continue with treatment.
- 4 and 5. The same may apply to those who are hospitalised and receive steroids. Patients are hospitalised for serious complications, such as reversal reaction, for which steroids are often given. Findings with other interview patients suggest that those with serious conditions, conditions with painful or debilitating manifestations, tend to keep on seeking help.
- 7 - 10. People with swelling, ulcers, ENL and nerve pain are often more seriously ill and may need hospitalisation for a period of time. They may consider their illness to be better once the symptoms have been reduced. In other words it may be that these people perceive the acute episode to be their illness, which they regard to be better when the symptoms subside, and so they see no need to take treatment. This explanation would be consistent with the findings of Neylan et.al. (1988) in Thailand. The illness career number eight in Chapter 11 illustrates this perception.

The numbers in most of these OC categories were unfortunately smaller than 10 so it is not possible to show any statistically valid comparisons. It can however be suggested that patients who have PB leprosy, skin patches, anaesthesia, disability and are hospitalised with steroids may tend towards being more regular on treatment than those who have acute episodes of illness which subside such as Reversal Reaction.

Distance or clinic accessibility and results

The effect of distance/accessibility, as represented by district of residence, on regularity was examined. The district from which patients in the cohort came are arranged roughly in order of increasing distance or difficulty of access. Some districts are further from the hospital but, because of the road system and bus services, are more accessible than others from which the only means of travel is on foot.

Kaski is the district in which Pokhara and Green Pastures are situated. Syangja and Tanahu are neighbouring districts, both with bus services so are more or less equidistant from Pokhara. The following chart shows the districts, the numbers of patients from each in the Cohort, those transferred, those remaining at GP for treatment and finally those who were out-of-control.

While most of the numbers are too small for statistical analysis of differences, some of the trends do show up in percentages. Firstly, the further away a district is in distance or accessibility, the fewer patients reported in the cohort. Secondly, as a general rule, the further away the district is the higher the percentage of patients who transferred to nearer clinics for treatment. Finally, the further away a district is, the higher the percentage of patients who were out-of-control. These numbers are so small, however, that these findings really cannot be said to conflict with those of Pearson (1985) when she found that distance apparently played no part in defaulting from treatment in the district of Lamjung, western Nepal.

Distance/accessibility and results

| District by distance | Total Cohort | | | | Remaining Cohort | | | |
|-------------------------|--------------|------|-----------|------|------------------|-----|------|------|
| | Cohort | | TT for Rx | | Rx at GP | | OC | |
| | n=154 | % | n=53 | % | n=101 | % | n=26 | % |
| Kaski | 41 | 26.6 | 6 | 14.6 | 35 | 35 | 5 | 14.3 |
| Tanahu | 23 | 15 | 4 | 17.4 | 19 | 19 | 4 | 21.1 |
| Syangja | 21 | 13.6 | 7 | 33 | 14 | 14 | 2 | 14 |
| Parbat | 10 | 6.5 | 6 | 60 | 4 | 3.9 | 3 | 75 |
| Chitwan | 10 | 6.5 | 5 | 50 | 5 | 5 | 1 | 20 |
| Gohkha | 8 | 5.2 | 5 | 37.5 | 5 | 5 | 3 | 60 |
| Lamjung | 7 | 4.5 | 1 | 14 | 6 | 6 | 2 | 33 |
| Gulmi | 5 | 3.2 | 3 | 60 | 2 | 2 | 1 | 50 |
| Myegdi | 4 | 2.6 | 3 | 75 | 1 | 1 | - | - |
| Baglung | 3 | 1.9 | 3 | 100 | - | - | - | - |
| Nawal Parasi | 3 | | 2 | 67 | 1 | | - | - |
| Rupendehi | 3 | | 1 | | 2 | | 1 | 50 |
| Kapilbastu | 3 | | 2 | | 1 | | - | - |
| Argakanchi | 2 | 1.3 | 2 | 100 | - | - | - | - |
| Palpa | 2 | | 2 | 100 | - | - | - | - |
| Manang | 1 | 0.6 | - | | 1 | | 1 | 100 |
| Dhading | 2 | | 1 | | 1 | | - | - |
| Sarlahi | 2 | | 1 | | 1 | | 1 | 100 |
| Rautahat | 1 | | 1 | 100 | - | - | - | - |
| Parsa | 1 | | 1 | 100 | - | - | - | - |
| Kalikot | 1 | | - | | 1 | | 1 | 100 |
| India | 1 | | - | | 1 | | 1 | 100 |

Out-of-Control (OC) patients and their attendance at clinic

Twenty-six patients were "out-of-control" (had been absent for 12 months or more) during the study period until November 1990. How many times did they attend before stopping? Eight came only once and never again. Four came twice; one of them was late for the second visit and three were not. Three attended three times, one being late for the appointment and two on time. One came four times and was late once, one five times and was late once. One came seven times and was never late. One came nine times and one eleven times; each of them were late once. One attended fourteen, one fifteen and one seventeen times, each of whom were never late. Finally one person went OC after 24 attendances,

having been late four times in all. (This person was categorised as OC even though he had finished the required 24 doses because he had not been examined for release from treatment (RFT). The health worker told him to come back again for this examination as there was not time to do it that day.)

During the course of the study the researchers had often observed the practice of fining all patients who came late for their appointment. At the end of the study this was discussed with the Nepali Out-Patient Clinic staff. They were firmly of the opinion that the fines acted as an incentive for future attendance and could not be persuaded that they might be counter-productive. This was brought up for two reasons. First, it seemed to the researchers, both Nepali and Western, that asking people to pay a fine when they came for free medicines, just because they were late, seemed to be negative reinforcement. Secondly, the fines had been mentioned by some of the interviewed OC cohort patients as a factor associated with their not returning.

Effect of lateness and fine on regularity and defaulting

The end result was that of the 101 patients of the remaining cohort, 53 (52%) were regular (never late) and 46 were late at least once. Of these 20 (43%) were regular after one or more fines, 18 (39%) were OC after one or more fines and eight only attended once anyway.

101 --> 2 unknown

--> 46 late ---|---> 17 OC

--> 53 regular |---> 18 late again-|---> 6 OC

|---> 11 regular |---> 5 late agn-|---> 1 OC

|---> 7 regular |---> 3 late

|---> 1 reg.

A very highly significant effect is shown in this table - Chi square of 14.19 with a probability of 0.01656% (uncorrected) or of 12.47 with a probability of 0.04130 (Yates corrected). From these figures it seems that the person who is late and fined is more likely to default than the person who is never late. It is not clear, however, whether the effect is related to the fine or just the lateness itself as there is not a large number of non-fined late people with whom to compare.

Analysis of these figures by two-by-two table is as follows:

Effect of fines for lateness on defaulting and regularity.

| | OC | Not OC (Regular) | |
|------------------------|-----|------------------|----|
| | yes | no | |
| Fined for lateness yes | 18 | 20 | 38 |
| | no | 8 | 53 |
| (2 unknown) | 26 | 73 | 99 |

The fact of being late for treatment may be an indication of the person having trouble with attending clinic. Such a practice is inconsistent with a holistic approach to care which would be highly desirable in a setting for dealing with leprosy which has such psychological and social, not just physical consequences. One suggests that a positive reception and sympathetic exploration of the difficulties encountered may be more productive for regularity than a hostile reception and fine.

What other factors affect clinic attendance behaviour?

The fact that a patient is late for a clinic appointment may relate to factors associated with social or religious duties as well as economic and seasonal factors. Several patient stories in this study illustrate various reasons for lateness, which had little to do with decisions not to take medicines any more. The behaviour of attending clinics is, as Mull et al. (1980) suggested, a complex mixture of behaviours which are affected by many socio-cultural factors and are not to be understood as a simple acceptance or rejection of the medicine and the services of the LCP.

The gross findings of 26% OC out of the cohort provided an objective reference point for further focus on non-compliant patients later in the research, as did the cohort itself for selection of half the patients to be interviewed in depth.

Apart from distance, accessibility and lateness factors there were no clear associations of other factors with regularity and defaulting found in this study. The results of this small medical compliance study are consistent with those of others, such as that of Larghorne, Duffus, Berkeley and Jesudasan (1986), who found no association between clinic attendance and age, gender, occupation, clinic size, disease classification, site of skin or nerve lesions, presence of leprosy contacts, duration of disease prior to registration, seasonal variation in attendance and distance travelled.

These findings leave many questions unanswered and illustrate the usefulness and limitation of such a quantitative study. They point to the desirability of a closer examination of other factors (see Vadher and Mansur, 1992) in the particular socio-cultural context in which clinic attendance is a problem. The remainder of the thesis moves into this cross-cultural world of leprosy in Nepal for further examination of patient non-compliance.

CHAPTER 7: TRADITIONAL AND WESTERN MEDICINE IN NEPAL

Introduction

In this section of the thesis the research findings are presented in the context of Nepal's medical system(s). It is organised with a view to enhancing understanding of the experiences and decisions of the people who are the central focus of the study, the leprosy patients themselves. What are their experiences of having leprosy and what affects their decisions about continuing or discontinuing treatment?

In this chapter the traditional and western medical systems as found in Nepal are described and compared. This provides the context against which community, patient and health worker explanations and expectations of leprosy are better comprehended.

MEDICAL SYSTEMS IN GENERAL

For the purposes of this presentation the term *ethnomedicine*, defined by Fabrega (1977) as "... the ways human groups handle disease and illness in light of their cultural perspective", will refer to the *medical system* of the group being discussed. Any medical system assumes a *cultural defining of illness*, as to causation, diagnosis as disease, with practitioners or healers using strategies for diagnosing, curing, managing and preventing disease which flow logically out of the theories of causation (Foster and Anderson, 1979:67). Writing in *Science*, Engel (1977) suggested that "... disease among non-literates is directly tied to the social behaviour of the person ..." and "... has heavy social implications". Therefore "*social conventions ... form part of all definitions of disease*". Health programmes in cross-cultural situations need to recognise the socio-cultural conventions and meanings attached to the particular problems which are their target. Health education, for example, for leprosy control in Nepal need to recognise these issues.

Notions of illness causation

Notions of illness causation have been categorised as personalistic, naturalistic or scientific (Foster & Anderson, 1979). The personalistic view of illness sees the person as the object of some aggression or punishment. Illness results from

"... the active, purposeful intervention of a sensate being who may be ... supernatural ... non-human ... or human. The sick person literally is a victim, the object of aggression or punishment directed *specifically against him* ...". (Foster and Anderson, 1979:53) (Emphasis added).

Naturalistic systems explain illness "... in impersonal, systemic terms ... When ... *equilibrium is disturbed*, illness results." (1979:53)

Scientific, or western biomedicine constitutes a third type allowing for a complete classification of world-wide medical systems (1979:79). Only with "... the development of the scientific concept of pathogens can the transmission of disease from one person to another be easily explained" (1979:67). To biomedicine illness occurs as bodily biological response to or conflict with micro-organisms or other material.

Engel (1977) observes that in the west "the biomedical model has ... become a cultural imperative ... and has ... acquired the status of *dogma*". In this thesis this biomedical system is understood to be the ethnomedicine of western culture. One consequence of this is that those who do adhere to this dogma may characterise people who do not as "unscientific", "old-fashioned" or "superstitious".

The people who are the central focus of this study, leprosy patients, like their village neighbours, adhere to notions other than, or in addition to, the biomedical ideas which have been introduced from outside their culture. Their views are presented in this thesis, not as "unscientific" or "superstitious", but as their view of the world. These must be understood, dealt with and adapted to if programmes for leprosy control are to be more effective.

MEDICAL SYSTEM(S) OF NEPAL

In Nepal the ethnomedicine of most foreign mission health professionals is the biomedical, scientific system of the West, while that of the Nepali people is different. This difference in ethnomedicine, the consequences of holding on the one hand biomedical "dogma", and the "heavy" socio-cultural implications of leprosy on the other, are central to any comprehension of leprosy and problems of patient compliance in Nepal.

Health professionals in Nepal who have been trained in western biomedicine encounter people there whose beliefs about illness they may consider "old-fashioned" or "superstitious". They certainly encounter a medical system which is new to them, which is complex, confusing and different. Over the past 30 years or so various researchers have described this medical system, the illness and curing concepts held by villagers and the faith healers of contemporary Nepal. Their work helps to make sense of the complex system. It forms the basis from which a description of Nepal's medical systems will be presented here. Studies have used a variety of approaches. Some researchers, like Stone (1976), Blustain (1976), Shrestha and Lediard (1980), lived in villages, observed, interviewed and recorded Nepali life and rituals. Some used questionnaires (Shrestha and Lediard, 1980). Others conducted both ethnographic and textual research (Stablein, Macdonald et al. in Hitchcock and Jones (eds.), 1976).

Studies describe the traditional medical system of Nepal from various viewpoints and from different parts of the country. Stone discusses the *illness and curing concepts* found in a hill village of Central Nepal. Blustain describes his findings in a small area in Western Nepal in terms of *levels of medicine*. Shrestha and Lediard look at the *beliefs of 100 faith healers* from four widely separated districts of Nepal. Hitchcock and Jones (1976) gathered studies of *shamanism and spirit possession* from many places in Nepal. Miller (1979) investigated *traditional healers, their rituals and festivals* in an area of Eastern Nepal. Macdonald (1984) provides notes on *the activity of certain magico-religious specialists* whom he designated healers.

Three general categories of medical systems are found in Nepal. These categories serve as a useful descriptive device but, as will be discussed later, do not represent actual distinct systems.

In central Nepal Stone found that "... the notion of the body having multiple links with the metaphysical universe ..." was "central to ... conceptions of illness" (1976), the notion being of external forces directed against the person. Apart from this notion of metaphysical links, she found notions of illness being linked with the natural world, to do with disturbance of balance or equilibrium. Along with these notions she found western scientific or "modern" medicine had also become part of the picture.

Personalistic: links with the metaphysical

A comprehensive description is given by Stone (1976). This is echoed in general by others, Blustain and Miller for example. The names of specific spirits or deities may vary by place and ethnic group but the overall pattern remains the same in Nepal, particularly in the Western Region which is the location of this study. In Nepal the individual has multiple links with the metaphysical world through the following:

1. **The planets.** "A misalignment between one's self and the planets spells misfortune ... Including illness ..." This is referred to as GRAHA BIGRAYO (relationship to the planets "gone wrong") or in the event of it being severely affected, KHADKO.

2. **"Evil spirits".** There are two categories of spirits. The first kind are referred to collectively as LAGU (to strike/to attack). The second category of 'evil spirits' "... do not attack individuals or directly inflict harm. They can, however, become angry." Their relationship to the individual is termed BIGRANU (to go wrong). These include Hindu gods.

The LAGU (spirits which strike or attack) include a long list:

- a) BHUT (wandering spirits attack at cross roads at night),
- b) PRET,
- c) MASAN (dwell at the funeral burning place or cremation ground),
- d) PICHAS (spirits of those for whom funeral ceremony is not done, or low caste person dying by accident),

- e) BIR (spirits of souls dying "improperly"),
- f) BOKSHI (human witch),
- g) DEWIS (female goddess, some say manifestation of the Hindu goddess Kali, others say an unrelated goddess),
- h) NAGS (water spirits), and
- i) BHUME (earth spirit).

These are said to attack the individual from their own malicious needs, out of hunger, or, except the NAG and BHUME, they may be sent by a BHOKSHI (human witch). The NAG and BHOKSHI attack out of anger rather than hunger. DEWIS and BHUME are given sexual distinction, and "most villagers maintain that DEWIS can be sent by BHOKSHIS". As these "... simply attack innocent people ... malicious(ly) ... the individual is morally neutral, but his physical or mental state is endangered".

The BIGRANU (to go wrong) spirits are worshipped in temples or the home and include:

- a) The KULDEVTA (clan or household gods),
- b) GRAHA (planet gods), and
- c) BAYU (ancestor spirit).

Stone found that the village people believe their relationship with these spirits can go wrong, that "the displeasure of any of these spiritual forces places one in a state of sin and moral danger ...".

3. Witchcraft. The BHOKSHI is listed above among the LAGU but is a particular kind of LAGU. The witch, usually a woman, deliberately uses the MANTRA (chant), or other LAGUS to cause harm out of jealousy or anger. It was reported to Stone that BHOKSHIS most commonly transmit their harm to a person or animal through *food*. Some also reported that harm may also be transmitted through *looking* or through *touching*.

4. Fate or DHARMA. The concept of fate is often referred to as the ultimate explanation for illness and to do with the ill person's "time to die" having come. Whether they live or not is out of their hands.

Naturalistic: the physical world

Apart from the notion of the link between the individual and the metaphysical world, there are many ways in which individuals become ill through connection with the physical world. ANGSRAWI (of the body or body parts) chiefly involve those to do with air or food and have to do with imbalance.

1. **Imbalance between hot (GARMI) and cold (SARDI).** Air or food may be hot or cold and affect the body hot-cold balance in various ways. "It is believed that moving (cold) air enters the body through the pores of the exposed skin, causing a general body swelling or, if entering the stomach, bloating." Illness results if hot or cold foods are consumed in excess. This notion is linked with another of

2. **Inside-outside the body.** In the event of both an unbalanced consumption of hot or cold foods and (cold) air entering the pores a more serious condition results: "...one feels hot inside and cold outside". Swelling or puffiness usually accompany this condition called SARDHI-GARAM BIGRAYO. (cold-hot gone wrong).

Scientific: biomedicine

Since the 1970s there has been growing awareness of scientific ideas. For example, in Nepal's schools children have been taught about hygiene and germs and infectious diseases and the like. The government Basic Health Services have gradually been established in rural areas. Even so, the notion that illness is a conflict or bodily biological response to encounters with micro-organisms or other material is not common in Nepal. The strength and effectiveness of western medicines for some conditions is, however, well known to many village people. Although scientific medicine is found in Nepal in a variety of settings, it is not readily available to most villagers and when illness occurs is therefore not always considered as a possibility.

Specialist practitioners: Diagnostic and curative techniques

The first consultation that takes place in the event of an illness problem being recognised by an individual and family is likely to be with family members and village neighbours. After or at the same time as the available family and village "folk"

remedies being tried, a "specialist practitioner" may be consulted. The range of specialist practitioners available in Nepal is:

1. The traditional healer (JHAKRI or JANNE-MANCHE - the person who knows).
2. The astrologer (HERNE-MANCHE - the person who looks).
3. The priest (PUJA GARNE-MANCHE - the person who does the Hindu religious ceremonies).
4. The Ayurvedic medical practitioner (BAIDYA).
5. The doctor, paramedical worker or dispenser (trained in "western" medicine.)

Availability of specialist practitioners

Anthropological studies in Nepal had, by the mid 1970s, led to the realisation that "shamans, whether called ... JHAKRI or by other words from local languages, played similar and important roles in society...throughout the whole country... (Miller,1979:2)". Shamanism, with its traditional healers, is the most widespread system in Nepal and for rural Nepal, the most frequently consulted (Stone, 1976). Shrestha and Lediard's (1980) report provides some insight into the relative availability in Nepal of practitioners using methods based on western as compared with the traditional practices. They estimated that Nepal had between 400,000 and 800,000 traditional faith healers at the time of their survey. They based this estimation on the numbers of traditional healers found in the four districts of their study. At that same time the number of western-trained health professionals was only about 3,400, made up of about 500 doctors, 330 nurses, 1,033 auxilliary nurse midwives and 1,522 village-based paramedical workers (1980:7). At that time the population of Nepal was just over 15,000,000 (National Planning Commission, HMG/N:1990). Their survey did not mention practitioners such as Ayurvedic doctors, who deal with illness from the naturalistic perspective.

Traditional healers: and "traditional medicine" in Nepal

Who is this shaman or traditional healer of Nepal? Striking parallels between the JHAKRIS or Shamans of Nepal and the classical shamanism as "... found in the arctic regions among the

Tungus people from whose language the word "shaman" comes" are noted by Miller (1979:5). According to Reinhard, JHAKRIS are shamans. He defines a shaman as:

... a person who at his will can enter into a trance (in which he either has his soul undertake a journey to the spirit world or he becomes possessed by a spirit) in order to make contact with the spirit world on behalf of members of his community (1979:16).

Foster and Anderson, who make mention of shamans in other cultures, for example among Eskimos and Indians of northern California, stated:

The term shaman ... is widely used to describe the type of curer who is "elected", who suffers serious illness, and who usually maintains close contact with his spirit familiar, in the Siberian variant being possessed by the spirit as he cures (1978:108).

Miller rejects the term "witch doctor" for Jhakri though he admits that "... a case could be made for its fundamental accuracy in that a JHAKRI often doctors sick people whom he diagnoses as being the victims of witchcraft". He calls the JHAKRI the "traditional faith-healer" as the least unsatisfactory English rendering of the Nepali (1979:1-6).

Macdonald built on his definition of JHAKRIS as "... magico-religious specialists" whom one can "... provisionally designate as healers" by stating that "... the true JHAKRI is he who, after having first of all suffered possession by a spirit foreign to his everyday world, manages to control it and to regulate it" (1967, 1983:113). Previous to this he states he had written of the JHAKRI:

He is a being who goes into a trance and at that time voices speak through his body which allow him to sometimes diagnose illnesses and sometimes to cure them, to give advice concerning the future and to clarify present facts in the light of events which took place in the past. He is therefore, at the same time a privileged intermediary between spirits (which give and cure sicknesses) and men; between the past, the present and future; between life and death; and in another perspective, between the individual and certain social mythology. He can, it seems, be of any JAT (caste) and he can take as pupil, in order to transmit to him his knowledge and techniques, a person of any other caste (Macdonald, 1983:115).

Miller found that JHAKRIS "... all have a basic unity of approach to the world, a world view which they share with their patients" (1979:2). What is this world view held in common between the JHAKRI and his patients? Miller defines it as:

... a belief in powerful invisible forces whose uncontrolled intrusion into our visible world brings disorder of all kinds: sickness, misfortune, disharmony in relationships. Ordinary men are helpless in the face of these forces but the JHAKRI, by virtue of his calling and training, has the ability to come into controlled contact with them and negotiate their withdrawal.

The diagnostic techniques of the JHAKRI or DHAMI-JHAKRI, DHAMI (medium) or JANNE-MANCHE, the traditional healer of Nepal

The native curers use three common techniques of diagnosis: pulse-reading (NADI HERNE), rice-reading (ANKAT HERNE), and the invocation of spirits (Stone, 1976). Those interviewed by Stone maintained that they used these techniques in the following order:

1. *Pulse-reading.* Both wrists are held and the character of the pulse interpreted.
2. *Rice-reading.* Rice, provided and touched by the patient, or "awakened" by a MANTRA by the practitioner, is let fall on to a plate and the position or numbers of grains noted and interpreted.
3. *Spirit invocation.* "The HANNE MANCHE will generally invoke his own BAYU" who speaks through him, revealing the cause of the patient's trouble.

Curing practices

The JANNE-MANCHE, loosely referred to as DHAMI (medium) or JHAKRI or DHAMI-JHAKRI was found to exercise *three types or levels of prowess* (Stone, 1976). Some know MANTRAS and will "blow" and "take out" only. Others will also make amulets for their clients. The third adds to the above the invoking of spirits.

1. *BHUT feeding.*
2. *Blood sacrifice to a BIR*
3. *Spirit invoking.*
4. *MANTRA, chanting, and JHAR PHUK, sweeping and blowing.*
5. *Amulets.*

BHUT feeding or the more general LAGU feeding plate is a ritual ceremony preparation and offering of a plate of special food, sometimes with blood added which can be carried out by the JANNE MANCHE, or a male relative of the sick person. If it is done for BHUT, MASAN or BIR it is called MANCHANU, and if for PICHAS or PRET it is called PARSANU. The ritual includes waving the plate above the head of the ill person, chanting to the LAGU to tell it it is being fed and must leave the ill person alone, and some hair and fingernail clipping is put into the plate as symbols of the body of the sick person.

Blood Sacrifice to the BIR

"... BIR is considered the most dangerous of the LAGU and is generally appeased with blood." A complicated ritual sacrifice is carried out, generally by the JANNE MANCHE, although a male relative may do it. If the JANNE MANCHE does it, it is part of a spirit-invoking ceremony. The chicken or goat meat is eaten by the JANNE MANCHE and his assistant (apprentice).

Spirit-invoking In the event of a BIR possessing a victim the JANNE MANCHE needs to go through a ritual to call it forth. The ritual takes place at night and fulfils two purposes. The first is to cure the patient. The second is to invoke "... other spirits for information or advice sought by other assembled people". Thus people ask about their own troubles and future.

MANTRAS or JHAR PHUK

During the spirit-invoking ceremony and at other times MANTRAS (chants) may be used by the curer. The tantric MANTRA is said to carry power within itself. It is uttered and then blown (PHUK) on to the patient. A process of "taking out" or "sweeping" (JHAR) often accompanies the blowing in which the curer brushes a broom over the patient and thrashes it to the ground. The MANTRA and JHAR PHUK techniques "...are considered the most effective counter-measure for illnesses connected with witchcraft".

Amulets are made for the patient by the JANNE MANCHE and are "...said to be 100% effective against all LAGU ...". The JANNE MANCHE determines the length of time they will be effective. They are made of either written MANTRAS or certain "medicines" (herbs or animal parts) wrapped in a piece of cloth and worn round the neck at all times.

Other diagnostic and curing practices

The astrologer or HERNE MANCHE is usually called to perform astrological calculations to see whether the trouble is because of misalignment of the patient's planets. He may also mention LAGU, or witchcraft or other misfortune as factors in the illness. He only diagnoses. A Priest is then called to perform the Hindu PUJA ceremony to assist the patient's recovery. According to Stone, (1976) they may be performed together or separately, for the general welfare of the family or in the event of illness. She states that the PUJA ritual

...carried out by the priest for illness is called GRAHA SHANTI SWASTI. It consists of three parts: RUDRI - offerings made to Shiva; PUTIKA - offerings made to Devi; and HOM - offerings made into the fire for the nine planets.

BAIDYAS (Ayurvedic practitioner) and Doctor (western medicine) Where available these practitioners may be consulted in the event of illness. Pulse-reading, clinical examination, laboratory tests of body fluids, X-rays, herbal remedies, adjustments to lifestyle and diet, medicine and surgery as well as radiotherapy are some of the practices of these practitioners in Nepal. The work of Blustain (1976) in western Nepal is helpful for completing the picture of the medical system(s) background of most of the leprosy patients of this study. Blustain found the same general pattern of belief about illness causation that Stone found, described above. However there are some important variations.

Blustain's study revealed the following curers in Western Nepal's Lamjung and Gorkha districts. While he does not term them all JANNE, as Stone does, they seem to reflect her three grades of JANNE. There are distinctions as well. These classification differences show the difficulty of giving a categorical description of an overlapping merger of various systems which is the one complex Nepali medical system. He found that

1. The JAISI Brahmins may act as JANNE MANCHE. They are able to tell if an illness is caused by a god and will recommend the correct PUJA. But they do not go into a trance and are "... ignorant of such practices as reading the pulse ... and herbal remedies" (Blustain 1976).

2. The BAIDHYAS, or Ayurvedic practitioners "... operate on both the herbal and ritual levels ...", the latter through the blowing of MANTRAS. But they do not go into trance either so cannot deal with conditions which need consultation with spirits for diagnosis and cure.
3. The JHAKRIS are the ritual healers par excellence.
4. The Muslim JAANE is distinguished by Blustain from the Hindu JANNE MANCHE. He keeps the term for the Muslim practitioners and uses the term JHAKRI for the Hindu curers. In the area he studied there was a small *Muslim community*.

These people held that there is only one type of spirit causing them most trouble. Their term is DEOTI, being the spirit of patrilineal kin. This spirit is dealt with by the Muslim practitioner known not as JHAKRI but as JAANNE. He merely reads from the Koran, uses Arabic MANTRAS, but most importantly does not go into a trance. The people present at the consultation ceremony are fed with SIRNI, a type of bread. The JAANE may make an *amulet* with a written portion of the Koran in it. Blustain noted that the Muslims and Hindus of his area "...have no respect for each other's medical systems". However, the Muslims have a dilemma. While their DEOTI may cause them trouble, so also may the BHOKSHI, PICHES and MASAAN of their Hindu neighbours. "For the majority of Muslims this is solved by their employing *both* the Muslim JAANNES and the Hindu JHAKRIS".

5. The western medical health professionals in the area of Blustain's study were Nepali and foreign staff of the United Mission to Nepal Hospital and Community Health Programme. Blustain (1976) notes that their

...basic understandings about the nature of illness, the methods of diagnosis, the techniques used in treatment - are all western in orientation. There is no discussion of BHOKSHIS or MANTRAS, and patients are never referred to a BAIDHYA or JAANE. In short the medicine offered at the hospital varies greatly, both in philosophy and content, from that of the village healer.

The following table (7:1) summarises the Nepal medical system in terms of Foster and Anderson's personalistic, naturalistic and scientific categories. However it is noted that these categories are not distinct, but rather merged.

Categories not distinct but merged

Both Stone (1976) and Blustain (1976) note that any categories of medical systems in Nepal - of causation belief, practitioner and technique - while being useful for description, do not represent actual discrete systems. Stone comments that "...they are in several senses merged and overlapping". Blustain notes that the levels of medicine he describes are all "inter-related" and "operate together", and "...all of these components are integrated into a complete and interrelated system" (1976). This may be important for the toleration of apparent ambiguity between traditional and western medicine. Shrestha and Lediard found one JHAKRI informant who had integrated western medicine into his stated belief:

Internal disorders cannot be treated only with the supernatural skills of the DHAMIS and JHAKRIS. We do believe in worshipping the supernatural power to cure patients, but in addition the patient should be given herbal medicine to combat his physiological disorders. The patient should also consult a government health facility where he can get injections and surgical help, if needed, to cure his ailment, even though it is created by supernatural beings (1980:63).

Stone discusses the interaction between traditional and western medicine in Nepal. She found villagers, in some situations, "...easily combine western medicine with traditional practices". Villagers seemed to "...have little difficulty integrating western medicine with their own traditions on an ideological level". She concludes that when these people use the systems in combination they

... are not in this process violating the general principles of their ... tradition, but are merely allowing their interpretations of particular cases of illness to remain sufficiently *ambiguous* for multiple diagnoses to be simultaneously considered. (1976)

Stone found some ambiguity in people's relationship to western or "modern" medicine in Central Nepal. Some in modern Nepal, who have been told at school to "... abandon their "superstitious" beliefs in illness causation" (Stone 1976), seek to identify with the "modern" world of Nepal and verbally deny traditional medical practices and confirm western medicine. However the public stance of some "... does not coincide with ... practices".

TABLE 7:1 summarises the Foster and Anderson framework of medical systems and places alongside it an outline of the findings in Nepal by Stone and Blustain. This latter is used later to report findings reflecting the world of the leprosy patients themselves.

| MEDICAL SYSTEMS THEORETICAL FRAMEWORK | MEDICAL SYSTEM(S) FOUND IN CENTRAL & WESTERN NEPAL IN 1976 | | |
|---|--|--|---|
| Foster & Anderson (1978) ELEMENTS OF MEDICAL SYSTEMS FLOW LOGICALLY FROM: CONCEPTS OF CAUSATION PERSONALISTIC MEDICAL SYSTEMS "...illness believed to be caused by...agents... supernatural (...deity), non-human (...spirit...), human (...witch...). The sick person ... is a victim, the object of ...punishment...against him...(personally)..." PRACTITIONERS : SHAMANS | LINDA STONE (1976) [and HARVEY BLUSTAIN (1976) in parenthesis.] (PRIMAL / HINDU / BUDDHIST / with MUSLIM) NOTIONS OF CAUSATION | | |
| | REMEDIES | PRACTITIONERS | |
| | METAPHYSICAL LINKS Planets Graha Bigrayo Spirits - <u>Lagu</u> (Jaasu) <u>Bhut, Bir</u> (Vir) <u>Pret, Bhokshi</u> (Bhokshi) <u>Hasan, Dewi</u> (Maasan) <u>Piches, Nag</u> (Pichash) <u>Bhume</u> - (Dinkini) - <u>Bigranu</u> Temple gods, <u>Graha</u> <u>Kuldevta, Bayu</u> (Bai) (Muslim Deoti) Mitches - <u>Bhokshi</u> | Appeasement of harmful supernatural forces 1. With promise of feeding ceremony - <u>Bhakal</u> 2. Food plate <u>Bhut/Lagu</u> 3. Blood sacrifice <u>Bir</u> <u>Jhar-Phuk</u> take out/blow <u>Mantra</u> formula of words <u>Amulet</u> <u>Jantra</u> - with <u>Mantra</u> <u>Buti</u> - with animal/ Do <u>Puja</u> Hindu religious ceremony. (Muslim - read Koran and feed <u>Sirni</u> & <u>Ghi</u> make Muslim amulet with written Koran extract - <u>Pitila</u>) | One who knows Self, relatives, friends neighbours, villagers. Astrologer <u>Lama-Jhakri</u> <u>Lama-Dhami/Lama</u> 1. Goes into trance, invokes the spirits does all below: 2. <u>Jar-Phuk/Mantra</u> /makes amulets & special techniques. 3. <u>Jar-Phuk/Mantra</u> only Brahmin priest (Jaisi) |
| NATURALISTIC MEDICAL SYSTEMS "...illness is explained in impersonal, systemic terms. ...(use) ...an equilibrium model; when ...elements of the body (heat, cold, humors, ying/yang) are balanced appropriate to...age, condition...environment" Early Greek, Syriac, Arabic. Muslim <u>Unani</u> medicine Medieval Christian Med. Indigenous Indian, Ayurvedic medicine. (<u>Tridosha</u>). Traditional Chinese medicine. (Ying & Yang) PRACTITIONERS: "PHYSICIAN/HERBALIST" | Fate - <u>Karma</u> is the overriding metaphysical link. PHYSICAL LINKS <u>Angrawi</u> (To do with body) Inside/Outside Hot/cold balance <u>Garmi/Sardi</u> (ditto) Balance of <u>Wind/Bile/Phlegm</u> (Blood) | Food to balance the imbalance Herbs and food (ditto) Ayurvedic medicine | <u>Baidhya</u> Ayurvedic |
| WESTERN, SCIENTIFIC MEDICAL SYSTEM "...basic patterns of cause & effect, as manifest in physics, chemistry, ...sciences of the mind." "...biochemical change in the body..." PRACTITIONERS: GENERAL & SPECIALIST DOCTORS etc. | WESTERN SCIENTIFIC (SECULAR, Miller, 1979) | Western medicines <u>Aushadhi</u> Injections and so on | Compounder Doctor - Private, Hospital - Government - Mission Paramedicals of various programmes |

Blustain noted that, for the villager in his area, this process of integration had already started. He maintains that in western Nepal both village and western medical systems "... do not operate to the exclusion of the other". He is of the opinion that "... medicine is based on faith - faith in the ability of the healer, ... the method of curing, ... the philosophy and cosmology upon which the system is based".

Many of those in Nepal who have been trained in western scientific medicine, based on the biomedical model, seem to have totally abandoned their previous models, beliefs about illness causation and so on (Stone, 1976; Blustain, 1976; Miller, 1979; Shrestha with Lediard, 1980). Consequently when they relate to their fellow Nepalis they at times assume a position which at best discounts and at worst denigrates the beliefs of their patients. This is not the most helpful approach to clinical communication, or health education, or to consideration of leprosy control in the context of Nepal's complex medical system. Conscious consideration of cultural dimensions of the problem are needed in order to comprehend it.

Miller observes that the JHAKRIS of Nepal hold a world view in common with their patients, namely that "invisible forces" bring disorder and sickness (1979:2). From his study of faith-healers in eastern Nepal he concluded that the various practitioners hold complementary roles in the community.

... the JHAKRI'S role is complementary to both priest and doctor. The priest (whether Brahmin or Lama) and his services are required for the predictable aspects of man's relationship to God, with religion as such, and so there is no direct competition with the JHAKRI who does not deal with life-cycle rituals. As regards the doctor trained in western methods of diagnosis and treatment, though he may at first view the JHAKRI as his rival, I believe that a closer look would reveal to him that, at least according to the world view of his village patients, he the doctor is treating symptoms while the JHAKRI is getting at causes. There is room, and need for both. (1979:3)

Shrestha and Lediard's work on training of JHAKRIS in certain aspects of family planning carries an appeal from a Nepali western-trained doctor recognising "... that the government will not be able immediately to provide "modern" health services to

replace the traditional services" and recommends that "... we ... find ways to *collaborate* with the faith healers.." (1980:17).

Blustain concludes by referring to the problem faced by western-trained public health workers. If they begin with the assumption that the village people have faith in their traditional practitioners, and that faith will not be shaken "... by occasional visits of medical teams or even by the building of hospitals", then their task is to find ways of "*integrating* western ideas into the village system". (1976)

Miller concludes that as long as the world view shared between the villager and the JHAKRI exists "... even when modern medical facilities become available", the JHAKRI will be needed and called upon. He found that many see the JHAKRI "... in the place of doctors ... but doctors, if and when they come to these remote villages, can never fully replace the JHAKRI" (1975). He sees traditional healers as a resource, not to be easily dismissed. He sees the JHAKRI'S role as "... complementary to both priest and doctor". He maintains that there is room, and need, for both doctor and JHAKRI because they deal with different aspects of the patient's problem; "... according to the world view of his village patients the JHAKRI is getting at causes", while the doctor, on the other hand, with his "... train(ing) in western methods of diagnosis and treatment ..." treats symptoms. He suggests that

The doctor will certainly realise that a shared world-view between patient and physician can be a powerful factor leading to a cure; he should also realise that his modern medical education, based on a secular view of the world, has deprived him of this advantage which the JHAKRI continues to possess.

Is there a clash of medical systems?

Development agencies in Nepal were seen by Stone, through their approach and practices, to be setting the western and traditional, the "supernatural" and "modern" medical systems in opposition to each other. She notes conflict between the two systems on a societal and institutional level. But neither she,

nor Blustain, nor Miller, found such competition at the village level.

ACCOMMODATION

A kind of accommodation of a totality of ideas, rather than an approach which would say; "*this, but not that*" is to be found in Nepal. The approach seen here seems to say "*this and that*". The western mind would attribute an event, illness and so on to a single main cause to the exclusion of others. The eastern mind here takes a broad view and sees undivided metaphysical and physical, human and non-human forces as origin or cause.

These ideas are rooted in ancient Hindu concepts expressed for example in the Upanishads. In the preface to their translation of the Upanishads, Shearer and Russell state: "The world view which shaped Sanskrit (the language of the original text) was a holistic one, ... objects are defined in terms of their function; actors and actions are seen as inter-related parts of a greater whole" (1978:8). They shed light also on the seeming contradictory or ambiguous causal beliefs held by the people in our study. In the introduction to one chapter they explain this greater whole and man's relationship to it as follows.

The world of Vedic India was a sacred one in which every action was understood as part of the cosmic order. The ancient sages saw the Universe as an eternal ritual of sacrifice. It is the self-sacrifice of the Absolute which gives birth to the relative and the very nature of life is one of transformation of energies. Every aspect of creation, divine or human, reflects this transformation. We cannot live without taking part in this cosmic ritual, both as instruments and as victims, and it is through this conscious participation in the sacrificial ritual that the cosmic order is maintained.

The seers taught that the Universe is maintained by a hierarchy of energies known as *devas* (literally "the shining ones"). These are the causal energies from which the subtle and gross worlds evolve, and are personified as the numerous divine beings of Vedic mythology. The *devas*, although diverse and often of opposing natures, are just the different aspects and sub-divisions of the one absolute causal energy.

In Nepal over the last decade or two a process of change and development of medical taxonomies and understandings has been taking place. The interaction of the new and alien (western) medical system with the existing complex Nepal medical system is resulting in adaptations, through accommodation, to the latter. One wonders whether in Nepal the western medical system will itself be informed and modified in this process of interaction or will it expect, as hinted at in Shrestha and Lediard, to replace it?

The writings of those who worked in Central and Western Nepal, in areas near to or among people groups included in this study, are used as the main sources for this outline of the "traditional medicine" of village Nepal. It is noted that although most of the studies referred to above were conducted in the 1960s and 1970s the beliefs and practices mentioned remain in the 1990s. From the patient interviews and community questionnaire of this study, conducted in 1990/91, many aspects of this medical system are alluded to. Two interviewees gave prolonged accounts of use of JHAKRIS. The researchers also met and interviewed at length two men who had previously worked as JHAKRIS.

This is the world in which the leprosy patient lives in Nepal. What do their contemporaries in their communities say about leprosy?

CHAPTER 8: COMMUNITY AND PATIENT EXPLANATIONS OF LEPROSY

This section of the thesis further builds the context against which the explanations and experiences of leprosy patients are better comprehended. Two aspects of the medical systems culture of Nepal are presented. In Part 1 of this chapter the explanations and expectations of leprosy given by the community and in Part 2 by patients are found to reflect Nepal's traditional medical system. Chapter 9 explores in more depth two socio-cultural mechanisms found to be operating in relation to people with leprosy. In Chapter 10 explanations of leprosy given by the health workers and a description of the clinics where leprosy is treated are shown to be based on scientific medicine. The leprosy patients who are the central focus of this thesis come out of this area of Nepal, the medical systems described in Chapter 7 are part of their cultural context. The results of a questionnaire survey conducted in a district one day south of Pokhara, in the Western region of Nepal, illustrate this.

Part 1. COMMUNITY SURVEY

This survey was of community knowledge and expectations regarding leprosy. This topic had previously been examined prior to the introduction of leprosy control services and public health education in that district in 1980. As part of this present study in 1990 it was re-examined using the same locations, methods, instruments (with minor adjustments) and research assistant.

Locations and Changes.

Extracts from translation of the reports of the interviewers on each locations given below provide illustration of the kinds of places surveyed and difficulties encountered. It should be understood that what is written here is taken from the observations of the interviewers and is in no way meant to be critical. Neither is it a systematic or thorough assessment of the village. They described and recorded what they saw and heard during a two to three day visit to each place.

Section 6: Kudiya Phenarwa

This village is facilitated by a bank, health post, police office, district administration offices, post office, high school and a small sugar factory. Along with these there is a small market with shops and hotels. There is irrigation also.

Population; there are 80 houses in Kudiya Ward No. 1 and 400 people made up of 36% Terai castes (Tharu, Ahir, Kalwar, Gupta and Baniya), 24% low castes and 23% Bahun, Chhetri. Socially and for livelihood this place seems to be similar to Bihar State of India. The husband who keeps his wife inside the house is seen as manly.

The main language here is Bhojpuri. The number of people who cannot understand Nepali is greater than those who can. Specially the Muslim and Terai people understand Nepali less. This difficulty was overcome by the research assistants preparing, with local help, a Bhojpuri language version of the questionnaire for use in this area.

Very few girls are sent to school, the women are very poorly educated. It was only after taking the help of a local educated young man that the survey could go ahead. Women who were answering questions stopped talking when their husbands came. They resumed after their husbands gave their permission.

The questionnaire was fine except it seemed long. The telling of the stories was most difficult. People only answered after we told the stories twice. They could not answer questions 9 and 11(a) (Vignettes) and 1. clearly.

Section 7: Beni Manipur

At the first survey the Beni Manipur Village Development Committee occupied a large area. After that the village development committee (area) was divided into four development committee areas. The old Beni Manipur Ward number 2 is now situated in Dhurkot Village Development Committee Ward number 1. The survey was done there.

The village is 5-6 hours walk from the road and has changed a lot since 1980. Every year a lot of people migrate here from other hilly areas and there is a vast difference now from 10 years ago. I did not see a trace of previous old forests and villages. But there was no special new idea found about leprosy. There is a

good attitude towards leprosy treatment but superstition is still there in regard to signs and symptoms and other social attitudes. Most of the people who migrate here are from Palpa and Tanahu, so being from such villages themselves the same superstitions are found a lot.

Section 8: Mukundapur Village Development committee Ward No. 9 Beldiha. Ten years ago Beldiha had many villages and a big area. Now Beldiha has been divided into 4 wards due to pressure of immigration. Wards No. 1,5,7 and 8 have split from the old Beldiha Ward No. 9. We surveyed Mukundapur Ward No. 1.

This village lies beside the highway and there is a market area. The main market is at Narayangad, which can be reached by a 4/- bus. Those who seek higher education travel there too. Language was not a problem as all groups understand Nepali. This area has a school, health post, bank and Sajha office and the standard of living is good.

Population; Bahun, Chhetri and Gurungs live near the road while Tharus and Magars live a little way away. Tharu is the main group here with Bahun, Chhetri, Muslim, Magar and Kami, Damai less. The Tharus are found to be literate here, but they seem to be least likely to send their daughters to school.

The people of this area seem to trust (western) medical treatment and have little faith in Lama-Jhakris. They still have little understanding of the etiology, and so on, of leprosy. Those who had difficulty answering the questions were the Tharu women, many of whom said they don't know.

Section 9: Kohluwa Village Development committee Ward No. 6 Nandapur. Kohluwa and Nandapur both belonged to one Ward (3) in 1980 but now are separated. Here also the pressure of immigration is seen.

Population, Tharu make up 64% with Bote 25%, Magar 9% and Bahun 2% only. The Bote people seem to be poorest with a low education level while the Tharus are able to read and write and have a good standard of living.

All the groups understand Nepali so our task was easier and quicker than in some other places. We finished in 2 1/2 days. Most difficulty was encountered in answering questions 9, a.b.c

and 10, a.b.c. and 11, a. (Vignettes) The people were really interested to help us and try to give real answers. The main occupation is agriculture and fisheries.

The Questionnaire

The questionnaire sought to gain insight into *what explanations and expectations community members have of leprosy and leprosy patients*. This 1990 survey of community opinions about leprosy therefore yielded a general picture of how leprosy is perceived in present-day rural Nepal. This picture represents the situation contemporary to the patients under study. (A brief comparison between 1980 and 1990 looks particularly at the expectations of social consequences of leprosy.)

The questions encompassed notions of the origin or etiology, recognition, reasons for fearing, curability and means of cure of leprosy. As discussed in the methods chapter (5), the questionnaire was carefully constructed so as to avoid as far as possible the introduction of a specific topic before a general, open-ended question had been asked. Open-ended questions were followed by structured, multiple-choice items.

In this way it was possible to explore the notions which people would volunteer when asked open-ended questions before finding what responses they would select when various options were suggested to them. The structured questions predetermined the limits of the data, while the open-ended questions, under favourable circumstances, provided for further discovery.

In the conduct of such a public survey in a rural setting in Nepal it is not always possible to question respondents privately. While the survey is going on some people come to know who the interviewers are and what they are asking. In their introductory remarks the interviewers asked people to answer with their own thoughts. However there may be some tendency for such respondents to answer questions in a way that they think would be expected or acceptable. It noted therefore that even in these circumstances the replies given still reveal strongly held views about dealing with leprosy. Perhaps the real views are stronger.

Below are the comments from the research assistants who conducted survey about answers and the people's understanding.

Even though we did not find a totally scientific attitude towards health and disease we found that they had some idea about it. Here the people give different meanings to KUSTHA ROG and KOR. (The meanings of these Nepali terms for leprosy are discussed fully in Chapter 10.) They call KUSTHA ROG a lot of different skin conditions (ringworm, vitiligo, Pandu Rog etc.) and use KOR for those whose hands and feet are damaged ("fallen off"). Thus we asked the questions on the form using KORI ROG. They regard KUSTHA ROG as ordinary and do not discriminate against them, but are afraid of KOR and the KORI are not touched.

All the people trust in superstitions because even the young people are uneducated. They expressed "old" and "bad" attitudes to leprosy. They believe in evil spirits, sin and curse and the deeds of a previous life as causes of leprosy.

They say that medical treatment can make leprosy better but also say that good food, PUJA and LAMA-JHAKRI make leprosy better. It seems they are not sure. The reality and facts have not won their hearts, they are still uneducated and have strong belief in superstition. They rely on agriculture.

The people here believe in evil spirits, where the sick seek the help of the JHAKRI. They say they have to have treatment that does not cost anything because they are very poor. They did not know that the treatment for leprosy was free. They object to the Rs.2/- administrative fee at the health post. They expect medicine from any health worker who comes from outside their community. (The government of Nepal had for many years publicised that they were giving free treatment to all. The introduction of fees is a move away from that stance and a recognition that the government promised something that it could not afford.)

We saw two untreated leprosy patients there and gave them referral letters to go to Belatari Health Post for treatment. We also saw two polio cases and advised on how to make lighter crutches and about good shoes and Jorpatti in Kathmandu. We also told the people about the importance of immunizations when we had a chance.

COMMUNITY SURVEY FINDINGS

Findings from the questionnaire responses are presented first and then comparisons made between various groupings of people. In particular the findings in relation to expectations of social consequences of leprosy, social separation, and the effect on these of the presence or absence of scientific notions of cause and cure of leprosy are discussed.

The responses of 160 people in four locations in Nawal Parasi are presented. There were 79 females and 81 males with an age range of 16 to 90 years. Those under 30 years numbered 78, and 82 people were 30 + years old. The caste/ethnic profile was high castes (36%), Terai castes (32.5%), hills groups (17.5%), low caste (7.5%), Muslim (4%) and Newar caste (2.5%). These numbers allow for comparisons to be made between age and gender groups and the major caste groupings of high, Terai and hills. The numbers of Muslims, low caste and Newars were too small for comparison to be made but their opinions were noted where they appeared to vary from the major groupings.

Responses to Questions

The etiology, origin or reason for the occurrence of leprosy was the first topic.

Responses to the open-ended question:

Overall 36% of respondents were uncertain (Don't know). Of those 63% who did express their opinion 37% (23% of all respondents) gave answers to do with dirt, filth, *contagion* and bad food. One quarter (16% of all) made statements to do with *metaphysical* reasons for leprosy such as the stars, fate, demerit in a previous life or offence to a god or spirit or failure to do one's religious duty. Some 23% (14.5% of all) made specific mention of notions to do with "germs" (KIRA, KITANU). The next largest percentage (15% or 9.5% of all respondents) were sure that leprosy is *hereditary* or from "bad blood".

TABLE 8:1
Responses to the structured question: For what reason does leprosy come?

| Question: For what reason, why does leprosy come? | 'Yes' | | 'No' | | Don't know | |
|--|-------|-----|------|-----|------------|-----|
| | Freq | % | Freq | % | Freq | % |
| Is it from fate? | 88 | 55% | 53 | 33% | 19 | 12% |
| Is it a curse? | 54 | 34% | 81 | 50% | 25 | 16% |
| Is it a spirit (BHUT) | 27 | 17% | 103 | 65% | 30 | 19% |
| By bad food? | 87 | 55% | 43 | 27% | 30 | 19% |
| Is it caused by a bite? | 53 | 33% | 68 | 43% | 39 | 24% |
| Is it caused by a germ? | 100 | 63% | 25 | 16% | 35 | 22% |
| Is leprosy hereditary | 102 | 64% | 42 | 26% | 16 | 10% |
| Does it come by itself? | 44 | 28% | 48 | 31% | 64 | 41% |
| (Note: Responses to these questions are not mutually exclusive.) | | | | | | |

Discussion

Notions of the origin or etiology of leprosy are multiple.

It is clear from the combinations of responses given to the structured question that these people hold multiple rather than singular notions of the origin of leprosy. A majority of respondents consider leprosy to be associated with heredity (64%), "germs" (63%), fate (55%), and with bad food (55%). Just over half of the respondents consider leprosy does not result from a spirit (65%), nor from a curse (50%). Among the 160 respondents 20 (13%) identified germs as the single *only cause*. Fifteen people said "Yes" to both germs and heredity and "No" to all the other options. There were 18 people who said "Yes" to everything on the list. It seems that these people are holding what seem to be contradictory notions. This will be discussed again in the context of the Nepal world view and accommodation later in this chapter. There also seems to be considerable uncertainty, particularly in relation to whether leprosy is caused by a bite, 'germs', or comes by itself. (This latter reply had been given by some of the patients interviewed in the first part of this study.) It is of interest to note that only 14.5% of the respondents volunteered germs or related notions in reply to the open-ended question but 63% said yes to germs when it was suggested to them. Again their reply may have been thought appropriate.

Recognition of leprosy was the second topic.

Note: this item was preceded by a general question: "In your community which diseases do you most fear?"

Leprosy almost inevitably occurred among conditions like: amoeba, cholera, malaria, typhoid, tuberculosis and meningitis.

Responses to the open-ended question: By what (signs) do you recognise leprosy?

The *crippling effects* of leprosy, the deformity, particularly of the hands and feet, were mentioned by 44%. *Skin signs* such as patches, blisters, nodules and so on were mentioned by 30%. Wounds, *ulcers*, pus and bad smells were mentioned by 15%. *Swelling* was mentioned by 5%, and 3% made more general comments like, "one can't go near a leper", "I only recognise leprosy when other people say it is".

TABLE 8:2

Responses to the structured question: Are the following signs of leprosy?

| Question: Are the following signs of leprosy? | 'Yes' | | 'No' | | Don't know | |
|---|-------|-----|------|------|------------|------|
| | Freq | % | Freq | % | Freq | % |
| Ulcers | 145 | 91% | 11 | 7% | 4 | 2.5% |
| Hands & Feet "drop off" | 149 | 93% | 6 | 3.7% | 5 | 3.1% |
| Swelling of face | 122 | 76% | 12 | 7.5% | 24 | 15% |
| Skin patches | 121 | 76% | 13 | 8% | 25 | 16% |
| No feeling | 78 | 49% | 25 | 15% | 57 | 36% |

TABLE 8:3

A structured question on reasons for fearing leprosy followed.

| Question: Do you fear leprosy because - | 'Yes' | | 'No' | | Don't know | |
|--|-------|-----|------|-------|------------|------|
| | Freq | % | Freq | % | Freq | % |
| It spreads (is contagious). | 147 | 92% | 12 | 7.5% | 1 | 0.5% |
| Hands and feet "drop off". | 133 | 83% | 26 | 16.5% | 1 | 0.5% |
| Leprosy pts are "not touched". | 124 | 78% | 33 | 21% | 3 | 2% |
| Leprosy pts are "put out". | 117 | 73% | 38 | 24% | 5 | 3% |
| Leprosy is painful. | 107 | 67% | 48 | 30% | 5 | 3% |
| (Note: These responses are not a exclusive.) | | | | | | |

Discussion

Leprosy Recognised through Deformity

There seems to be a strong opinion that leprosy is contagious, that hands and feet "drop off" (93% from recognition question and 83% from reason to fear question), and that people with leprosy are "not to be touched" (are ritually polluted) (78%) and are to be "put out" of the village (separated or socially ostracised) (73%).

The replies to both the open-ended and structured questions indicate that most people associate 'leprosy' with the deformity. The presence of deformity is an indication that the condition has been present for some time. There were very few who identified the type of skin lesions which are characteristic of leprosy in its early stages. The finding that the general public are unlikely to recognise leprosy in its early stages, but may readily recognise it once deformity is present, is borne in mind when considering the replies to the next question about the curability of leprosy.

The structured question: Is leprosy curable?
 The question on the curability of leprosy is of special interest for this thesis.

TABLE 8:4
 Responses to structured question: Is leprosy curable?

| <i>Is leprosy curable? with comments given</i> | | | |
|---|------|-----------------------------|------------|
| | Freq | % | Freq % |
| 1. Leprosy is usually curable. | 85 | 54% (Qualified Yes | 53 33%) |
| 2. Leprosy is only occasionally curable. | 44 | 27% (Perhaps, 'Yes and No'. | 26 16.25%) |
| 3. Leprosy is never curable | 8 | 5% (Not if... | 7 4.5%) |
| 4. Don't know. | 23 | 14% (No comments given. . . | 74 46.25%) |
| | 160 | 100% | 160 100% |
| (Percentages are of total respondents. These responses are mutually exclusive.) | | | |

There were 86% of respondents who expressed a definite opinion on this item. A majority of this 86% of respondents (62%) (calculated after deducting the "don't know" portion) (or 54% of all respondents) said that leprosy is "*usually* curable". It is however to be noted that more than one third (38%) (32% of all respondents) expressed serious doubts about this ("only occasionally" (32%) and "never" (6%) taken together).

Comments were invited after this structured question and were added by 87 people (54%) of respondents. They present a similar picture to that gained from the previous structured question. Percentages are of those who commented. The comments about the curability of leprosy fell into the following categories:

'Yes...'. (62%) qualified by comments such as: 'with medicine', 'with good medicine', 'at hospital', 'health post', 'from the doctor', 'plus good food', 'must not eat certain foods', and so on.

'Yes if...' (10%) qualified by the provision that medicine must be given in good time.

'Yes and No'! (7%) Comments such as: 'Some yes and some no.' 'Some get better and some get worse.'

'They say so, but...' (5%) I have not seen it!

'No, never if...' (8%) 'from god, (BHAGWAN)', 'demerit', 'Once "captured" by this it does not get better.'

TABLE 8:5
Responses to the structured question: Does leprosy get better by the following means?

| Question: Does leprosy get better by - | 'Yes' | | 'No' | | Don't know | |
|---|-------|-----|------|------|------------|------|
| | Freq | % | Freq | % | Freq | % |
| Religious ceremony? | 34 | 21% | 116 | 73% | 10 | 6% |
| Traditional healer? | 40 | 25% | 109 | 68% | 11 | 7% |
| Medicine (western)? | 142 | 89% | 9 | 5.5% | 9 | 5.5% |
| Pilgrimage? | 29 | 18% | 117 | 73% | 14 | 9% |
| Good food? | 48 | 30% | 101 | 63% | 11 | 7% |
| (These responses are not mutually exclusive.) | | | | | | |

Those who do consider leprosy can get better predominantly see modern medicine as a means of cure. However only 17 people (11%) gave the opinion that, among the possibilities mentioned in the question, modern medicine is the *only means of cure*. Of those who see medicine as the *main means of cure* 30% consider good food to be part of the cure. As well as medicine other means indicated were Lama (traditional healer) (25%), Hindu religious ceremony (PUJA) (21%) and pilgrimage (18%).

Comments of those who thought leprosy is cured by medicine included statements with strong qualifications.

Yes, but 'not if it comes from god (BHAGWAN)', 'not if it is from demerit (KARMA)', 'not if it is from sin (PAAP)'.

Others distanced themselves from their answer by saying 'They say, but..' 'They say some get better, but I have not seen it.' 'I have seen some get worse.' 'I have not seen all get better.'

Among those who added comments to their answer on curability there were five who said a definite 'No'.
No, 'I have never seen it get better.' 'Not if from the 'fruit of past life'.' 'Some yes but some no.' 'They say so but I have never seen.' 'Once "captured" by leprosy it never gets better!'

Discussion

Leprosy seen through community eyes

The overall picture of public belief or opinion about leprosy becomes clear from these responses.

1. Origin. Leprosy results from a mix of causes like fate, the stars (55%), is associated with dirt and filth (37%), has germs (63%), and a majority think it can be inherited (64%).

2. Recognition. Leprosy is seen as a condition characterised by deformity (44%), by ulcers and by skin manifestations. It is very contagious (92%) and the hands and feet "drop off" (83%).
(See p. 156)

3. Social Dealings. People with leprosy are not to be touched (isolated) (78%), and are likely to be put out of the village (socially isolated) (73%).

[Note: In traditional societies this is a condition tantamount to "social death". The phenomenon of social ostracism or separation is discussed in Chapter 9.]

4. Curability. More than one third (46%) of the community hold serious doubts as to the curability of leprosy (occasionally, never, don't know). About half the respondents (54%) consider leprosy to be "usually curable", but give many qualifications. A few (11%) see modern medicine as the only means of cure.

Comparisons between age and gender groups

Comparisons are made between those of 16-29 years of age (78 respondents) and those of 30 years and over (82 respondents), as well as between the men and women. These are set out and commented on below.

[Note: All statistical testing of differences is by two-by-two contingency tables after making the assumption that a "Don't know" response is tantamount to a negative reply.]

The Origin or etiology of leprosy from the open ended question:
by gender.

Some differences were noticed between male and female responses to the question on the origin or etiology of leprosy.

TABLE 8:6

A list of items given by respondents on *the origin of leprosy*:

| | Female | | Male | |
|---|--------|-----|------|-----|
| | Freq | % | Freq | % |
| 1. Germs | 8 | 5% | 19 | 12% |
| 2. Dirt/filth (contagion) | 15 | 9% | 31 | 19% |
| 3. Heredity | 6 | 4% | 10 | 6% |
| 4. Metaphysical | 18 | 11% | 13 | 8% |
| (Note: Percentages are of total respondents.) | | | | |

Replies from separate items of structured questions by gender

Etiology of leprosy from the structured question

TABLE 8:7

Is leprosy hereditary?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 7 | 9% | 9 | 11% | 4 | 11% | 7 | 17% | 3 | 7% | 2 | 5% |
| No | 19 | 24% | 23 | 28% | 8 | 21% | 8 | 20% | 11 | 28% | 15 | 37% |
| Yes | 52 | 67% | 50 | 61% | 26 | 68% | 26 | 63% | 26 | 65% | 24 | 58% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

A majority (64%) say 'Yes'. Chi Square, gender = 0.29 and age = 0.56%.

Neither the age or gender differences were found to be statistically significant.

TABLE 8:8

Is leprosy from "fate"?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-------|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 8 | 10% | 11 | 14% | 6 | 16% | 5 | 12% | 2 | 5% | 6 | 15% |
| No | 33 | 43% | 20 | 24% | 14 | 37% | 9 | 22% | 19 | 47.5% | 11 | 27% |
| Yes | 37 | 47% | 51 | 62% | 18 | 47% | 27 | 66% | 19 | 47.5% | 24 | 58% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

A considerable difference appeared here between the age groupings. Younger people are less likely to attribute leprosy to "fate" than their older neighbours. Chi Square, gender = 0.24 and age = 3.52 with probability level of 6%. The age difference is significant.

TABLE 8:9

Does leprosy result from a curse of god?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 11 | 14% | 14 | 17% | 7 | 18% | 7 | 17% | 4 | 10% | 7 | 17% |
| No | 47 | 60% | 34 | 41% | 19 | 50% | 14 | 34% | 28 | 70% | 20 | 49% |
| Yes | 20 | 26% | 34 | 41% | 12 | 32% | 20 | 49% | 8 | 20% | 14 | 34% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Overall a small majority of people (50.5%) said 'No' to the question. Older women are most likely to consider leprosy to be a curse while younger men are least likely to hold this view. The gender difference was not significant, Chi Square = 3.2. A considerable difference is seen between the older and younger respondents with older people less likely to say "No" when asked if leprosy is from a curse. This overall age difference was found to be significant with a Chi Square of 4.48 with (1 df) at the probability level of 3.44%.

TABLE 8:10
Does leprosy result from a spirit (BHUT)?

| | All | | | | Females | | | | Males | | | |
|------------|------|-------|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age | 16-29 | 30- | | 16-29 | 30- | | | 16-29 | 30- | | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 15 | 19% | 15 | 18% | 9 | 24% | 9 | 22% | 6 | 15% | 6 | 15% |
| No | 51 | 66% | 52 | 64% | 21 | 55% | 21 | 51% | 30 | 75% | 31 | 75% |
| Yes | 12 | 15% | 15 | 18% | 8 | 21% | 11 | 27% | 4 | 10% | 4 | 10% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Belief that leprosy may be caused by a spirit is not very common. Men appear less likely to believe it than women. Chi Square, gender = 5.7 and age = 0.24. None of the differences were found to be significant, nor was there any significant interaction between older women and younger men.

TABLE 8:11
Is leprosy caused by a "germ"?

| | All | | | | Females | | | | Males | | | |
|------------|------|-------|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age | 16-29 | 30- | | 16-29 | 30- | | | 16-29 | 30- | | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 17 | 22% | 18 | 22% | 10 | 26% | 12 | 29% | 7 | 18% | 6 | 15% |
| No | 9 | 11% | 16 | 20% | 7 | 19% | 9 | 22% | 2 | 4% | 7 | 17% |
| Yes | 52 | 67% | 48 | 58% | 21 | 55% | 20 | 49% | 31 | 78% | 28 | 68% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Almost one quarter did not know. There is a majority (63%) who say 'Yes' leprosy is caused by a 'germ'. However men are more likely to believe this than women and younger people are more likely to believe it than the older respondents. The overall gender difference is highly significant with Chi Square 7.48 (1 df) at a??? level of probability. Chi Square, age = 1.13. Younger females are less likely to attribute leprosy to a germ than the younger men. Gender difference in the young is significant with a Chi Square of 4.34 (1 df) at a 3.7% level of probability.

TABLE 8:12
Does leprosy result from bad food?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 16 | 21% | 14 | 17% | 8 | 21% | 9 | 22% | 8 | 20% | 5 | 12% |
| No | 20 | 26% | 23 | 28% | 10 | 26% | 9 | 22% | 10 | 25% | 14 | 34% |
| Yes | 42 | 54% | 45 | 55% | 20 | 53% | 23 | 56% | 22 | 55% | 22 | 54% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

While a small majority (54.5%) associate bad food with leprosy, 27% do not and 21% are not sure.. No one is very sure. [The problem with the question relates to the general nature of the Nepali term for "bad food" used in the question.] Chi Square for gender and age are both very small. No statistically significant differences were found.

TABLE 8:13
Does leprosy result from the bite of some insect?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 18 | 23% | 21 | 26% | 10 | 26% | 14 | 34% | 8 | 20% | 7 | 17% |
| No | 32 | 41% | 36 | 44% | 15 | 40% | 14 | 34% | 17 | 42% | 22 | 54% |
| Yes | 28 | 36% | 25 | 30% | 13 | 34% | 13 | 32% | 15 | 38% | 12 | 29% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

There seems to be a great deal of uncertainty. [The idea of a bite being the cause was taken from prior informal interview replies but it seems to be uncommon.] Chi Square, gender = 0.03 and age = 0.5. No significant differences were found.

Reasons for fearing leprosy from separate items of the structured question: by gender

TABLE 8:14
Do you fear leprosy?
Because the hands and feet "drop off"?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 1 | 1% | 0 | 0% | 1 | 3% | 0 | 0% | 0 | 0% | 0 | 0% |
| No | 13 | 17% | 13 | 16% | 8 | 21% | 5 | 12% | 5 | 12% | 8 | 20% |
| Yes | 64 | 82% | 69 | 84% | 29 | 76% | 36 | 88% | 35 | 88% | 33 | 80% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 40 | |

There is a strong positive response to this question. Chi Square, gender = 0.08 and age = 0.125. No significant differences were found.

TABLE 8:15

Do you fear leprosy because it is painful?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 4 | 5% | 1 | 1% | 3 | 8% | 0 | 0% | 1 | 2% | 1 | 3% |
| No | 24 | 31% | 24 | 29% | 10 | 26% | 10 | 24% | 14 | 35% | 14 | 34% |
| Yes | 50 | 64% | 57 | 70% | 25 | 66% | 31 | 76% | 25 | 63% | 26 | 63% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Between 62% and 70% of people think leprosy is painful. However it is lack of feeling is a common feature of leprosy. This misconception may relate to the appearance of leprosy ulcers, they look as if they should be painful. See Table 8:23 which asks about "no feeling". Chi Square, gender = 1.13 and age = 0.528. No significance was found in any of the differences.

TABLE 8:16

Are you afraid of leprosy because it spreads?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 1 | 1% | 0 | 0% | 1 | 3% | 0 | 0% | 0 | 0% | 0 | 0% |
| No | 4 | 5% | 8 | 10% | 2 | 5% | 3 | 7% | 2 | 5% | 5 | 12% |
| Yes | 73 | 94% | 74 | 90% | 35 | 92% | 38 | 93% | 38 | 95% | 36 | 88% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

There seems to be little doubt that an overwhelming majority of these people consider leprosy to be communicable. Chi Square, gender = 0.06 and age = 0.6. No significant differences were found by age or gender. The notion of ritual pollution in relation to leprosy may be associated with this belief.

TABLE 8:17

Do you fear leprosy because people with leprosy are "not touched"? (Ritually polluted, socially isolated.)

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 3 | 0% | 0 | 0% | 3 | 8% | 0 | 0% | 0 | 0% | 0 | 0% |
| No | 14 | 19% | 19 | 23% | 8 | 21% | 5 | 12% | 6 | 15% | 14 | 34% |
| Yes | 61 | 81% | 63 | 77% | 27 | 71% | 36 | 88% | 34 | 85% | 27 | 66% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

There is strong support for the notion that leprosy renders one ritually polluted. There are however fewer older men who agree with this position. There is an opposite gender difference on this question. More young women and fewer young men say 'No'. Chi Square, gender = 0.45 and age = 0.043. None of these differences are however statistically significant.

Do you fear leprosy because people with leprosy are "put out of the village"? (A more extreme form: social separation.)

There is still a strongly held belief (73.5%) that this is what happens to people with leprosy in their society. Again the opposite opinions are seen between the older men and women, and the younger women and men. Fewer young women say 'Yes' while more young men do.

TABLE 8:18

Do you fear leprosy because people with leprosy are "put out of the village"? (A more extreme form: social separation.)

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 3 | 4% | 2 | 2% | 3 | 8% | 1 | 2% | 0 | 0% | 1 | 2% |
| No | 16 | 20% | 22 | 27% | 8 | 21% | 6 | 15% | 8 | 20% | 16 | 39% |
| Yes | 59 | 76% | 58 | 71% | 27 | 71% | 34 | 83% | 32 | 80% | 24 | 59% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Chi Square, gender, = 1.33 and age = 0.49. The gender difference in the older age group was found to be significant, with Chi Square 5.89 (1 df) at a 1.5% level of probability. A significant age difference was also found between the males with Chi Square 4.37 (1 df) at a 3.6% level of probability.

Overall the older men seem less likely to consider 'putting out' a feature of leprosy than younger ones do. The reason for this is not clear at this time.

Recognition of leprosy from separate items of the structured question: by gender

There seems to be little doubt that these people associate ulcers with leprosy. Chi Square, gender = 1.98 and age = 0.03. No statistically significant differences were found.

Here also a very strong association of leprosy with deformity is seen. Chi Square, gender = 4.97 and age = 1.05. A significant difference was noted between males and females with Chi Square of 4.97 (1 df) at a probability level of 2.57%.

TABLE 8:19

Are wounds (ulcers) a sign of leprosy?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 2 | 3% | 2 | 3% | 2 | 5% | 1 | 2% | 0 | 0% | 1 | 2% |
| No | 5 | 6% | 6 | 7% | 3 | 8% | 4 | 10% | 2 | 5% | 2 | 5% |
| Yes | 71 | 91% | 74 | 90% | 33 | 87% | 36 | 88% | 38 | 95% | 38 | 93% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

TABLE 8:20

Are 'spoiled' hands and feet a sign of leprosy?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|------|---------|-----|------|-----|-------|------|------|------|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 3 | 4% | 2 | 2.5% | 2 | 5% | 2 | 5% | 1 | 2.5% | 0 | 0% |
| No | 4 | 5% | 2 | 2.5% | 3 | 8% | 2 | 5% | 1 | 2.5% | 0 | 0% |
| Yes | 71 | 91% | 78 | 95% | 33 | 87% | 37 | 90% | 38 | 95% | 41 | 100% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Is swelling of the face a sign of leprosy?

There is again strong (76%) agreement that swelling of the face is a sign of leprosy. The younger women are least sure, Don't know (24%), Yes (61%). Chi Square, gender = 3.93 and age = 1.72. The gender difference is significant with Chi Square 3.93 (1 df) at the 4.7% probability level:

TABLE 8:21

Is swelling of the face a sign of leprosy?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 14 | 18% | 10 | 11% | 9 | 24% | 7 | 17% | 5 | 12% | 3 | 7% |
| No | 7 | 9% | 5 | 6% | 5 | 14% | 2 | 5% | 2 | 5% | 3 | 6% |
| Yes | 56 | 73% | 66 | 81% | 23 | 62% | 32 | 78% | 33 | 83% | 34 | 85% |
| | 77 | | 81 | | 37 | | 41 | | 40 | | 40 | |

TABLE 8:22

Are skin patches a sign of leprosy?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 13 | 17% | 12 | 15% | 10 | 26% | 8 | 20% | 3 | 7% | 4 | 10% |
| No | 5 | 6% | 8 | 10% | 3 | 8% | 5 | 12% | 2 | 5% | 3 | 7% |
| Yes | 60 | 77% | 61 | 75% | 25 | 66% | 27 | 68% | 35 | 88% | 34 | 83% |
| | 78 | | 81 | | 38 | | 40 | | 40 | | 41 | |

About a quarter of the women "don't know". Chi Square, gender = 7.49 and age = 0.06. The gender difference is highly significant with Chi Square 7.49 (1 df) at a 0.62% level of probability. More men than women thought skin patches were a sign of leprosy. This is an important finding as skin patches are an early sign of leprosy. The role of the women as child carers means that they are more likely to see such early signs on children and teenagers.

TABLE 8:23
Is having "no feeling" a sign of leprosy?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 32 | 41% | 25 | 30% | 22 | 58% | 16 | 39% | 10 | 25% | 9 | 22% |
| No | 11 | 14% | 14 | 17% | 4 | 11% | 10 | 24% | 7 | 17% | 4 | 10% |
| Yes | 35 | 45% | 43 | 53% | 12 | 31% | 15 | 37% | 23 | 58% | 28 | 68% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

The proportion of respondents who did not know the answer to this question is 35.5%. More men (63%) were inclined to say 'Yes' than were women (49%). Chi Square, gender = 13.26 and age = 0.92. The gender difference is very highly significant in this question with Chi Square 13.26, (1 df) at a level of probability of 0.027%. Younger people were less likely to say 'Yes' than older people. The age difference, however, is not significant. Here also the fact that leprosy often renders both skin patches, hands and feet, and even the eye insensitive to pain is not widely known among these people.

Curability and means of cure of leprosy: by gender

TABLE 8:24
Is leprosy curable?

| | All | | | | Females | | | | Males | | | |
|--|-----------|-----|------|-----|---------|-----|------|-----|-------|------|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Usually | 47 | 60% | 38 | 47% | 15 | 39% | 17 | 42% | 32 | 80% | 21 | 51% |
| Occasionally | 20 | 26% | 24 | 29% | 14 | 37% | 12 | 29% | 6 | 15% | 12 | 29% |
| Never | 2 | 2% | 6 | 7% | 1 | 3% | 1 | 2% | 1 | 2.5% | 5 | 12% |
| Don't know | 9 | 12% | 14 | 17% | 8 | 21% | 11 | 27% | 1 | 2.5% | 3 | 8% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |
| (Hold serious doubts - occasionally + never) | 22 | 28% | 30 | 36% | 15 | 40% | 13 | 31% | 7 | 18% | 17 | 41% |

A majority of men (65.5%) but only 40% of women thought leprosy to be usually curable. The young men (88%) are most confident

that leprosy is curable and hold least doubts. Young women (39%) are least sure and hold (with the older men) most serious doubts. About one quarter of the women (24.6%), but only about 5% of the men did not know whether leprosy is curable or not.

There is a significant age and gender difference for this question. Young men are more likely to consider leprosy curable than older men, Chi Square 3.94 (1 df) at a 4.7% probability level. The significant gender difference, Chi Square 5.19 (1 df) at a 2.27% level of probability, shows men more inclined than women to consider leprosy curable. These findings may reflect the pattern of education in rural Nepal where young people have had more schooling than their elders and where males receive more education than the females of the community.

Curability of leprosy from separate items of the structured question: by gender

TABLE 8:25

Is leprosy cured through religious ceremony (PUJA)?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 7 | 9% | 3 | 4% | 6 | 16% | 3 | 7% | 1 | 2% | 0 | 0% |
| No | 62 | 79% | 54 | 66% | 27 | 71% | 23 | 56% | 35 | 88% | 31 | 76% |
| Yes | 9 | 12% | 25 | 30% | 5 | 13% | 15 | 37% | 4 | 10% | 10 | 24% |
| | 78 | | 81 | | 39 | | 41 | | 40 | | 41 | |

Overall the answer is No (average 72.5% with a range from 56% to 88%). A difference is seen here between the ages. Younger people are less likely to agree that PUJA will be effective for leprosy.

Chi Square, gender = 1.5 and age = 8.58. The age difference is highly significant, Chi Square 8.58 (1 df) at a 0.34% level of probability.

There seems to be a difference between the sexes, with women being more inclined than men to agree that PUJA may work, in particular 37% of the older women said it would. The gender difference, however, is not statistically significant.

TABLE 8:26

Is leprosy cured through a traditional healer (LAMA)?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 8 | 10% | 3 | 4% | 7 | 19% | 3 | 7% | 1 | 2% | 0 | 0% |
| No | 56 | 72% | 53 | 65% | 21 | 55% | 21 | 51% | 35 | 88% | 32 | 78% |
| Yes | 14 | 18% | 26 | 31% | 10 | 26% | 17 | 42% | 4 | 10% | 9 | 22% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Is leprosy cured through a traditional healer (LAMA)?

Similar differentiation appears here between ages and sexes as was seen for the previous question. However they are less marked and the 'No' reply is somewhat less definite than for PUJA. (Average 'No' 68.5% with a range of 51% to 78%.)

Chi Square, gender = 7.01 and age = 4.04. There is a highly significant gender difference and a significant age difference in these responses. The highly significant gender difference, Chi Square 7.01 (1 df) at a 0.8% probability level sees women more likely to believe in the LAMA. Older people were more likely to agree that the LAMA was part of leprosy cure. Chi Square 4.04 (1 df) at a 4.5% level of probability. No significant interaction was found.

TABLE 8:27

Is leprosy cured through pilgrimage?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 10 | 13% | 4 | 5% | 9 | 24% | 4 | 10% | 1 | 2% | 1 | 0% |
| No | 61 | 78% | 56 | 68% | 25 | 66% | 22 | 54% | 36 | 90% | 36 | 83% |
| Yes | 7 | 9% | 22 | 27% | 4 | 10% | 15 | 36% | 3 | 8% | 3 | 17% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 40 | |

Here again the pattern of replies is similar to the two previous questions with a higher proportion of older women (54%) considering pilgrimage possibly effective for leprosy. Young men (90%) were most sure it is not.

Chi Square, gender = 8.2 and age = 5.26. The gender difference is highly significant, Chi Square 8.22 (1 df) at a 0.42% level of probability. The gender difference in the older age grouping is also highly significant, Chi Square 9.91 (1 df) at a 0.16% level of probability.

Is leprosy cured by (western) medicine?

The answer to this question is a resounding 'Yes'. Men (94%) are more likely to have confidence in medicine than women (84%). Several of the younger women did not know.

These findings are important as background when health education target groups and specific messages are planned.

TABLE 8:28

Is leprosy cured by (western) medicine?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 6 | 8% | 3 | 4% | 5 | 13% | 3 | 7% | 1 | 2% | 0 | 0% |
| No | 3 | 4% | 6 | 7% | 3 | 8% | 2 | 4% | 0 | 0% | 4 | 10% |
| Yes | 69 | 88% | 73 | 89% | 30 | 79% | 36 | 89% | 39 | 98% | 37 | 90% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

Chi Square, gender = 4.2 and age = 0.013. The gender difference is significant, Chi Square 4.24 (1 df) at 3.9% probability level.

TABLE 8:29

Is leprosy curable with good food?

| | All | | | | Females | | | | Males | | | |
|------------|-----------|-----|------|-----|---------|-----|------|-----|-------|-----|------|-----|
| | Age 16-29 | | 30- | | 16-29 | | 30- | | 16-29 | | 30- | |
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % |
| Don't know | 8 | 10% | 3 | 4% | 7 | 19% | 3 | 8% | 1 | 2% | 0 | 0% |
| No | 51 | 65% | 50 | 61% | 18 | 47% | 19 | 46% | 33 | 83% | 31 | 76% |
| Yes | 19 | 25% | 29 | 35% | 13 | 34% | 19 | 46% | 6 | 15% | 10 | 24% |
| | 78 | | 82 | | 38 | | 41 | | 40 | | 41 | |

On the question of good food being a cure of leprosy there seems to be much less certainty. [Again this is probably to do with the very general term used in the question.] Women on the whole and older women in particular (46%) say "Yes" it is, but an equal number say "No". Younger men (83%) are very definite that good food does not cure leprosy. The overall answer is "No" (average 63% with a range of 46% to 83%).

Chi Square, gender = 8.2 and age = 2.3. The gender difference is highly significant, Chi Square 8.2 (1 df) at a 0.42% probability level.

Summary of main gender and age differences found

Significant *gender differences* were noted in a number of instances. Women are less likely than men to attribute leprosy to "germs". Women are less likely to recognise skin patches, particularly patches with loss of feeling, to be early signs of leprosy. Nor are they as likely as men to associate swelling of the face or "spoiled" hands and feet with leprosy. They are less likely to consider leprosy to be curable or, if they do, to believe medicine to be effective. They are more likely than men to think that a pilgrimage or a LAMA could be effective in curing leprosy. Finally, women are significantly more likely than men to fear leprosy because people with leprosy are "put out" of their villages. As well as these, women seem less willing to express their opinions or less sure on a number of questions. Women gave the "don't know" response more often.

A possible explanation of women fearing leprosy because of their being "put out" is that women, because of their dependent position in society, feel more vulnerable, and would be able to cope less well if thus rejected by their family and society.

The fact that a skin patch with loss of sensation is an important early sign of leprosy appears to be far from generally known. This finding, along with the gender differences, has significant implications for planning and targeting of public health education messages.

Significant differences were found between *age groups* related to belief in metaphysical and traditional practices. Older people were significantly more likely to attribute leprosy to "fate" and a "curse" than their younger neighbours. Older people were also more likely to have confidence in "puja" and the "Lama" as effective sources of cure for leprosy. There seems less of a relationship between age to the question of social ostracism or "putting out" of the village. See discussion in Chapter 9.

What differences appeared between castes?

The numbers of each grouping were: high caste - 58, low caste - 12, Terai castes - 52, hills groups - 28, with Newar - 4 and Muslim - 6. This sample reflects the demographic pattern of the population found by the research assistants in the areas surveyed. This section mentions major differences found.

On the *etiology of leprosy* there was general agreement except in the following:

Heredity - High, Low and Terai groups said "Yes" (63-69%) but only 46% of the Hills group said "Yes".

Curse - High and Low groups were most definite on "No" (60-66%). Some of the three groups, High, Terai and Hills, said "Yes" (31-37%) but only 8% of the Low said "Yes".

On patients being "**put out**" of the village more of the Hills group (82%) said "Yes" with fewer of the High and Terai groups (72%) saying "Yes".

While there are variations in percentages in the above categories, analysis using two by two contingency table shows no statistically significant differences.

TABLE 8:30
Curability of leprosy by caste

| | High | | Low | | Terai | | Hills | | Newar | Muslim |
|-----------------------|------|-----|------|-----|-------|-----|-------|-----|-------|--------|
| | Freq | % | Freq | % | Freq | % | Freq | % | Freq | Freq |
| Usually | 35 | 60% | 3 | 25% | 35 | 67% | 6 | 22% | 2 | 4 |
| Only occasionally | 13 | 22% | 5 | 42% | 13 | 25% | 11 | 39% | 1 | 1 |
| Never | 1 | 2% | 2 | 16% | 2 | 4% | 2 | 7% | 0 | 1 |
| Don't know | 9 | 16% | 2 | 17% | 2 | 4% | 9 | 32% | 1 | 0 |
| | 58 | | 12 | | 52 | | 28 | | 4 | 6 |
| Have doubts Occ.& Nvr | 14 | 24% | 7 | 58% | 15 | 29% | 13 | 46% | 1 | 1 |

From this table it seems that Low caste and Hills groups have least confidence that leprosy is curable. High caste and Terai groups seem to be fairly sure. However no significant difference was found.

As to *means of cure*: There seems to be some real difference in the following cases:

Puja - High and Terai groups said "No" (80%) but fewer of the Hills group (50%) said "No", a significant difference, Chi Squared 5.02 (1 df) at a probability level of 2.4%. Note that 4 of the 6 Muslims said "Yes".

Lama - High castes (84%) said "No" while fewer of the Low and Hills groupings (50 to 67%) said "No", a significant difference, Chi Squared 5.97 (1 df) and probability level of 1.5%.

Pilgrimage - High and Terai castes (82%) said "No" while fewer of the Hills grouping (57%) said "No", a significant difference, Chi Squared 4.84 (1 df) at a 2.7% level of probability.

Summary of caste differences

From these findings it appears that Hills groups are different from their High caste and Terai caste neighbours in that they are more likely to expect results from religious ceremony, pilgrimage and traditional healers as a means of cure of leprosy.

Discussion

Notions of causation are found to be multiple

It is clear from the findings that the notions of causation held by these people are in general multiple rather than singular. Only 20 people (13%) identified "germs" as the only cause of leprosy. The remaining 140 respondents (87%) gave multiple responses. For instance, to those who replied "Yes" to "germs"

being a cause of leprosy, heredity was also a cause (66%), bad food was also seen as associated (75%), as were fate (54%), a curse (37%) and a spirit (26%).

TABLE 8:31

Responses to questions of cause and cure

Frequency and combinations of responses

Combination: "germ" - "medicine" and "fate" - "puja"

| Freq. | response | | response | |
|---------------|----------|-----|----------|-----|
| 55 | yes | yes | no | no |
| 55 | yes | yes | yes | no |
| 6 | yes | yes | no | yes |
| 25 | yes | yes | yes | yes |
| 2 | yes | no | yes | yes |
| 6 | no | yes | yes | yes |
| 0 | no | no | yes | yes |
| 149 responses | | | | |

Do metaphysical and scientific beliefs affect responses?

There were 45 people (28%) who said leprosy results from "fate" and also from a "curse" and 100 (63%) who said "germs". The notions of cause and cure may be represented on a continuum with germ-medicine at one end (scientific) and fate-puja at the other (metaphysical)

Fear of or expectations of the social consequences of leprosy

The people who hold "fate" and "curse" notions also said they feared leprosy because it is "not touched" (93% of 45) and that they are "put out" of the village (93% of 45).

Those who attributed leprosy to "germs" feared leprosy because it is "not touched" (77% of 100) and they are "put out" of the village (72% of 100).

It appears that higher expectations of social ostracism and stronger doubts about the curability of leprosy may be associated with beliefs of a metaphysical cause of leprosy. It also appears that belief about germs being the cause may be associated with some increased confidence in leprosy curability and less expectation of social consequences of leprosy. It is noted, however that even among those who reply that leprosy is caused by a germ (100 respondents) there remain strong expectations (72-77%) of social ostracism.

When it comes to expectations of cure and of social consequences of leprosy are there differences between those who hold metaphysical as against "scientific" cause-cure notions?

Analysis was done first of those who hold a "fate"- "puja" cause-cure notion and then of those who hold a "germ"- "medicine" cause-cure notion. Each was examined for any effect on the expectation of cure and of social consequences accompanying leprosy. (It is noted that neither of these two notions was held exclusively but in combination with other notions.)

Effect on expectation of cure of leprosy of "fate"+"puja" (F+P) cause-cure notion .

TABLE 8:32

Leprosy is curable when: it is caused through fate and cured through religious ceremony

| | Yes (usually) | No (occlly/nvr/dnt know) |
|---------|---------------|--------------------------|
| F+P Yes | 7 | 20 |
| No | 42 | 23 |
| | 49 | 43 |

Chi square 11/47 (df 1) Prob. 0.007%

The effect of "fate"- "puja" on expectation of cure of leprosy is very highly significant.

Effect on expectation of cure of leprosy of "germ"- "medicine" (G+M) cause-cure notion of .

TABLE 8:33

Leprosy is curable when: it is caused by a germs and cured by medicine

| | Yes (usually) | No (occlly/nvr/dnt Know) |
|---------|---------------|--------------------------|
| G+M Yes | 61 | 33 |
| No | 0 | 12 |
| | 61 | 12 |

Chi squared 18.34 (df 1) Prob. 0.0018%

The "germ"- "medicine" notion was very highly significant in relation to expectation of cure.

Is there a real difference in expectation of cure between the groups who hold these polar cause-cure notions?

A final comparison was made between the expectations of cure of those who believe in the "Fate"- "Puja" and in the "Germ"- "Medicine" notion of cause-cure.

Leprosy is curable: fate-Puja and Germ-medicine notions compared

From these findings it seems that those who expressed the belief about fate as an origin of leprosy and puja as a possible effective cure have significantly greater doubts about leprosy being curable than those who do not hold these beliefs.

There follows a comparison between the two polar notions in relation to cure of leprosy.

TABLE 8:34

Leprosy is curable: fate-Puja and Germ-medicine notions compared

| | Yes (usually) | No (occlly/nvr/dnt Know) | |
|---------|---------------|--------------------------|-----|
| F+P Yes | 7 | 29 | 27 |
| G+M Yes | 61 | 33 | 94 |
| | 68 | 53 | 121 |

Chi Squared 12.94 (1 df) Prob. 0.032%.

The difference between these two groups is very highly significant.

TABLE 8:37

Do you fear leprosy because it is "not touched" (i.e. social isolation as used for those ritually polluted)?

| | Yes | No | |
|---------|-----|----|----|
| F+P Yes | 26 | 1 | 27 |
| No | 44 | 21 | 65 |
| | 70 | 22 | 92 |

Chi squared 8.58 (df 1) Prob. 0.34%

Do you fear leprosy because it is "put out of the village" (social separation.)

TABLE 8:36

Leprosy is "put out of the village".

| | Yes | No | |
|---------|-----|----|----|
| F+P Yes | 24 | 3 | 27 |
| No | 40 | 25 | 65 |
| | 64 | 28 | 92 |

Chi squared 6.74 (df 1) Prob. 0.94%

There was indeed a highly significant difference when it came to the question of expectation of social consequences.

It seems that those who expressed the belief that fate is an origin of leprosy and puja a possibly effective cure have significantly greater doubts about leprosy being curable and are significantly more likely to expect social consequences of leprosy than those who do not hold these beliefs.

Expectation of social consequences accompanying leprosy

Cause-cure notion: "Germ"- "Medicine" (G+M).

The effect of this "germ"- "medicine" notion was found to make no significant difference in relation to expectation of social separation. This finding is of itself significant. This seems to indicate that even though the 'scientific' notion of "germ"- "medicine" significantly increases the expectation of leprosy being physically cured, it does not really change the expectation of the social consequence of leprosy which is social separation from the community and is usually permanent. In other words, whether people believe in "fate"- "puja", or "germ"- "medicine", or both, a high proportion (over 70%) of them still consider leprosy to be both ritually polluting and socially ostracising.

An example of insight gained from the vignettes

It is interesting to note that in spite of the difficulty experienced in administering these questions they do yield some helpful indications of what people think should happen, or at least report what they think should or would happen.

Vignette Two. The man who is diagnosed and treated for leprosy after seeing a poster giving leprosy early signs and symptoms.

Question 1. What would he do when he went back home?

Responses from one location:

| | |
|-----------------------------------|-----------|
| 1. He would take regular medicine | 32 people |
| 2. Live seperately | 5 people |
| 3. Take the advice of the family | 1 person |
| 4. Be happy | 1 person |
| 5. Don't know | 1 person |

Question 2. Would he tell his family about his condition?

Responses from one location:

- | | |
|---------------------|-----------|
| 1. Yes he would. | 38 people |
| 2. No he would not. | 2 people |

Discussion

It is clear that a vast majority of these people (80%) expect leprosy patients to take medicine. There is still an expectation from some (12.5%) that the person with leprosy will separate himself or be separated. (This may mean just separate eating vessels but it may also mean as much as a separate living place and no physical contact with family members.)

The high expectation that the person would tell his family (95%) stands in contrast to the actual situation found among patients taking medicine from Green Pastures Hospital who have been interviewed in depth. Only 15 out of 23 such patients have told their families. In fact eight (35%) are deliberately keeping their condition from their families, even from their spouses. This group included a young man who came direct to the hospital (without resort to any traditional remedies first) because he recognised his condition from his school book account of leprosy. He knew the cause and cure for leprosy but was not prepared to let anyone know about his condition. Both these issues - separation and silence - are central to the findings of the thesis as presented in Chapters 9 and 12.

Remarks related to community expectations of leprosy

Educators should note that the addition of scientific medical concepts of leprosy to (that is their accommodation with) already existing community views had a significant positive effect on expectation of cure. This is perhaps an indication that the aims of education can and should change. Rather than expecting scientific facts to replace old ideas, a culturally aware expectation would be to build the new into the existing or re-interpret the new in terms of the old. Accommodation works significant change.

Even though those who hold the "fate"- "puja" beliefs are more likely to doubt the curability of leprosy and expect social consequences, these ideas seem to have a weaker effect than the "germ"- "medicine" beliefs do. For one thing the former number is fewer (94) than the latter (141). For another, the previous findings of age and gender difference leaves one with the impression that the younger people and the men are different from the older people and the women.

This finding hints at women and girls being less well informed in relation to new ideas. This seems to be a reflection of the state of affairs in Nepal. As the UNICEF's Children and Women of Nepal: A situational Analysis states: "The low level of female literacy has had a negative impact on their access to knowledge." (UNICEF 1987:172). The literacy rate is higher among males. (Male 52%, Female 18%). (Central Bureau of Statistics, 1987) General education programmes were introduced into Nepali schools in the early 1970s and leprosy health education introduced in Nawal Parasi district in the early 1980s. Boys tend to stay at school in greater numbers and for longer than girls do; "...data suggest that about half of all boys and less than a third of all girls between the ages of six and ten years are actually enrolled in primary school" (UNICEF 1987:135), and "...only about three per cent of all females have completed their secondary education, compared with 13 per cent of all males" (UNICEF 1987:91).

The age and gender differences found in community survey data are as would be expected. Western medical ideas and belief in the efficacy of scientific medicines are quite common in Nepal. These have been infiltrating into Nepal over the past 50 or so years. The age and gender differences, and effects of metaphysical beliefs on cure expectation, do point to a need for specific focus for future public education about leprosy.

These people of Nawal Parasi, representing those of the Western Region from among whom the interview patients were taken, hold an image of leprosy which could be called 'normal' for Nepal in 1990. It consists of a mixed metaphysical/physical

(supernatural/natural) notion of causation. A mental picture of the person with leprosy is of a sufferer with ulcers and deformed hands and feet who must be set apart socially, and who, with a combination of means but predominantly with medicine, can usually be physically but not socially cured. Very few of them, particularly the older people and the women, recognise signs which would indicate early leprosy.

From the point of view of scientific medicine, it is clear that these people recognise as leprosy the condition when it has become advanced. If the aims of the Leprosy Control Programme to find and treat leprosy in its early stages are to be successful, there needs to be serious attention paid to public education on that matter.

Part 2: EXPLANATIONS OF THE ORIGIN OF LEPROSY FROM PATIENT INTERVIEWS

What about the patients who come from such communities as this: do their beliefs reflect those of their community?

Framework for reporting explanations and building illness careers

The interview guide used was constructed with Kleinman's (1980) five points and Illness Careers with Stafiliou-Rothschild (1970) and Twaddle (1977) as a background. Other elements from the clinical perspective were added to fill out the picture. The interview guide itself covered topics designed to elicit both patient Explanatory Models and Illness Careers. The explanations are reported here and the illness careers illustrated in Chapter 11.

Who are these patients who were each interviewed in depth for this study during the field research period in 1990? They fall into two main groupings.

First are those who belong to a cohort of people who were registered at Green Pastures Hospital as new leprosy patients during a 12-month period. All the patients in the cohort were

due to have completed their 24 monthly doses within 36 months' treatment by the end of the field research period in mid-November, 1990. At that time a retrospective examination of their Out-Patient Card would show a record of the clinic attendance choices they had made.

Twelve of the cohort patients were interviewed on a day they attended the clinic to receive the next routine dose of their treatment. This represented 12% of cohort patients who were registered at GP to continue their treatment.

Five other cohort patients were interviewed in their homes. They were among a chosen ten cohort patients who had previously discontinued their visits to the clinic and had been designated "defaulters" or categorised "Out of Control" by the Leprosy Control Programme. This means that they had been absent for a minimum of 12 months. [Note: These particular patients were chosen as their homes were within two days' journey from the hospital. Other "defaulter" patients who lived further away were not selected for two reasons. It was reckoned that they might not be reasonably expected to continue treatment because of distance. We desired to follow as many as possible of the total 26 cohort "defaulter" patients within the time and budgetary constraints of the research programme.] The follow-up of these ten "defaulter" patients occupied two research assistants for one month. They travelled by bus but mainly on foot to and from the mountain villages where these patients lived. Five of these patients were absent from their homes and could not be interviewed (more of this in the next chapter). Five patients (19%) of all the cohort "defaulters" agreed to tape-recorded interviews.

The second main grouping of people interviewed are from those (non-cohort) patients who, during the period of the study (March to mid-November 1990), attended clinic at the hospital and commenced treatment for the first time or re-commenced treatment after a long absence. Twelve of these were interviewed on the day of their first visit to the clinic, the day that they were diagnosed as leprosy patients. The other five were "defaulter"

patients who had previously been visiting the clinic for treatment, had discontinued but now had returned to the clinic.

While this is not a large sample, two features of this study must be borne in mind as far as practical considerations which presented limitations to including more. First, the nature of the terrain itself and absence of roads and telephones made patient follow-up difficult. Secondly, the time-consuming nature of gathering, transcribing and translating tape-recorded interview data also constrained the study. Notwithstanding these limitations, the transcriptions (in Nepali) and the English translations of these 34 interviews constitute a rich source of information from which a great deal is learned and new insights gained.

Of the 34 interviews used in this section 24 contained specific answers in relation to the cause of their problem. The following findings are taken from them. A more comprehensive analysis of each interview reveals remarks which could indicate background belief about cause. These are presented later.

When patient responses in relation to causality are taken together a varied and complex picture is formed. Elements of responses are categorised using the Metaphysical, Naturalistic (or Physical) and Scientific framework. This picture, presented in Table 8:38, reflects the general community findings and underlines the fact that the people who happen to contract leprosy hold like views.

Metaphysical or personalistic concepts

These include PAP "the result of sin", usually associated with the idea of a previous life being spoiled, fate or KARMA. There is a cluster of concepts related to being a 'victim of revenge' and having been bewitched, a bad spell cast, or a paying back after committing a real or imagined offence against another. Some patients had been told the cause was an 'evil spirit', or a 'god', for example the KULDEWOTA or household god, giving trouble. Some had performed special PUJAS or ceremonies of worship to remove the problem and gain peace of mind. One woman

mentioned the SWASTANI, a Hindu religious book read annually which tells the story of a queen, struck down with leprosy as a SHRAAP or curse who recovers after obeying certain rituals. [This story from the Swastani is detailed in the appendix. It seems to embody, and is perhaps the ancient genesis of traditional ideas about leprosy which remain strong in Nepal today.] Some patients mentioned consulting a variety of traditional practitioners. Some were reluctant to admit this, possibly because these ideas had been discounted and ridiculed at the hospital. (This has been observed.) Some patients only talked about it after being assured that we were interested in their own ideas, not what they thought it was acceptable to say. Practitioners mentioned include Astrologers, Brahmin Priests, DHAMI-JHAKRI or LAMA-JHAKRI, 'Witchdoctors' and 'Wizards'. Ideas of JASU (casting a bad spell), BAYU, (spirit of the dead), and DASHA, (misfortune or ill-luck) were given.

Naturalistic phenomena

A number of patients mentioned blood: bad blood, passed on by blood, the same blood, insufficient blood. These could be linked with mention of heredity and talking about not having ancestry or family members with leprosy. Some spoke of it being of the body, emerging from the body. One talked of it being bad while in the body and healing once it had broken out. Another spoke of what had gone in having to come out. To one person it is a bone disease. There was a lot of description of the physical symptoms and sensations. Expressions like "tingling like nettle stings", "shooting pains", "insect bites", "numbness" are common as are signs like hard blisters, swelling, weakness and wounds. Some called it "ringworm", "white leprosy", "black leprosy"; others used the variety of Nepali words KOR, KUSHTHA, MAHAROG. However there was considerable reluctance on the part of a number to name their problem, with use of evasive terms like "this disease" while pointing to the hospital, and denial that they had been told the name was common. The concept "not having hands or feet" seems to be of significance. One patient spoke of having been "touched by having no hands or feet", as if this had been visited upon her.

TABLE 8:37

NOTIONS OF ILLNESS CAUSATION, HELP SEEKING AND REMEDIES REPORTED BY LEPROSY PATIENTS IN WESTERN NEPAL: 1990

| NEPAL'S MEDICAL SYSTEM (PRIMAL/HINDU/BUDDHIST) CONCEPT OF CAUSATION FRAMEWORK FROM STONE* | LEPROSY PATIENTS' REPORTED: NOTIONS OF CAUSATION ** PRACTITIONERS CONSULTED ** REMEDIES RECOMMENDED ** | | |
|--|---|--|---|
| METAPHYSICAL LINKS | | | |
| Planets | Planets out of line Graha Bigrayo | Self, relatives, friends, neighbours, villagers. | Pulse reading Horoscope |
| Spirits - <u>Lagu</u> | Evil Spirits Jaasu a bad spell | Astrologer Lama-Jhakri Lama-Dhami Lama | Rice reading Mantras Spirit invocation Bhut feeding Lagu plate left at cross roads Blood sacrifice, chicken, goat; patient drinks hen's blood, covered by goat skin Do Puja Hindu religious ceremony |
| - <u>Bigranu</u> | Angry god or goddess Family god Kul Dewota Rangan | Brahmin priest | |
| Witches - <u>Bhokshi</u> | Bewitched | | |
| Fate - <u>Karma</u> | Fate or sin Dasha ill luck Previous life spoiled Sin/curse Touched by Hat-Khuta Nahunu "having no hands or feet" | Hindu Religious Book Swastani Bratkotha | Bhaakal oath with promise. |
| PHYSICAL LINKS | | | |
| Angsrawi (To do with body) | | | |
| Balance | From the body | | Don't take alcohol or cigarettes |
| Hot/cold <u>Garmi/Sardi</u> | Emerges by itself when the body is weak Bad blood | Medical Hall, <u>Baidhya</u> | Digri 'Degree', instrument Blood test |
| Inside/Outside | From my father same blood (inherited) A blood and bone disease Inherited (from the milk) | | Injection Xray Crushed bean leaf juice |
| Balance of Wind/Bile/Phlegm (Blood) | from mother Dasha | | |
| WESTERN SCIENTIFIC (SECULAR) | | | |
| Biomedical | | School Books Radio Health post | Aushadhi Anti-leprosy drugs Multi-Drug Therapy Regularly take medicines Come when instructed |
| | Infectious Caught from brother Spreads | Private doctor Government hospital Mission hospital Leprosy clinic/hospital | Do what told Stay away from village Be removed from family Leprosy asylum |

* (Stone, Linda 1976) ** These listings relate only loosely across columns

Certainly the idea of hands and feet being spoiled by leprosy is prominent in many people's minds. One man recounted a bad dream he had had just before coming to the hospital for the first time. In his dream he saw a place where everyone's hands, feet and heads were covered in bandages.

Notions having some scientific basis

These are clustered mainly round KIRA or germs and the possibility of their problem resulting from contagion. Of those who mentioned this idea, two were sure they had caught leprosy from a close relative. The others were struggling with the idea saying things like 'they say it is infectious', or 'perhaps' it is infectious, but were not aware of contact with a leprosy patient. One man, when asked Q. "Do you suspect he passed the disease on to you?", (with regard to another patient who used to live near him in his village) replied: A. 'No! If he had passed on the disease it would have appeared immediately. It has been 2-3 years since he left so how could I say he passed it on to me?!' [The fact that leprosy has a long incubation period (of two to eight or more years) seems to mitigate against a ready understanding or acceptance of a notion of contagion.]

Categories not distinct but merged

It is important to note that these categories are not mutually exclusive. On the contrary, most interviewees gave a mix of answers. Of the 24 interviews where specific notions of causality were given, 14 mentioned metaphysical, 17 also gave physical and 10 scientific explanations. (See table below)

In particular, of the 14 mentioning metaphysical concepts four also gave scientific ideas, and eight included some physical aspects as well. Of the 10 mentioning scientific ideas, four also spoke of metaphysical and seven of physical elements. This mix of causality categories in responses is set out in the table below.

PATIENT EXPLANATIONS: ACCORDING TO METAPHYSICAL (M), PHYSICAL (P) & SCIENTIFIC (S),
CATEGORIES OF NOTIONS OF CAUSALITY: NUMBER OF PATIENTS RESPONDING
TABLE 8:38

| ALL Ms | ALL Ps | ALL Ss | ALL CATEGORIES |
|---------|---------|---------|----------------|
| MPS : 2 | MPS : 2 | MPS : 2 | MPS : 2 |
| MP- : 6 | MP- : 6 | -PS : 5 | MP- : 6 |
| M-S : 2 | -PS : 5 | M-S : 2 | M-S : 2 |
| M-- : 4 | -P- : 4 | --S : 1 | M-- : 4 |
| 14 | 17 | 10 | -PS : 5 |
| | | | -P- : 4 |
| | | | --S : 1 |
| | | | TOTAL 24 |

Note: These numbers are given, not as a statistical statement but to illustrate the point that categories are not mutually exclusive. Only one person gave an exclusively scientific answer. He was one who was sure he had caught the disease from his brother.

Conclusion

It is clear that notions of etiology reported by these patients reflect those reported by community members and set out in Table 7:1 in the Chapter 7 on Traditional and Western Medicine in Nepal. In other words, patient beliefs reflect those of the general community. Patients attend clinics in spite of having a mixture of beliefs and not because they accept totally the concepts of western medicine.

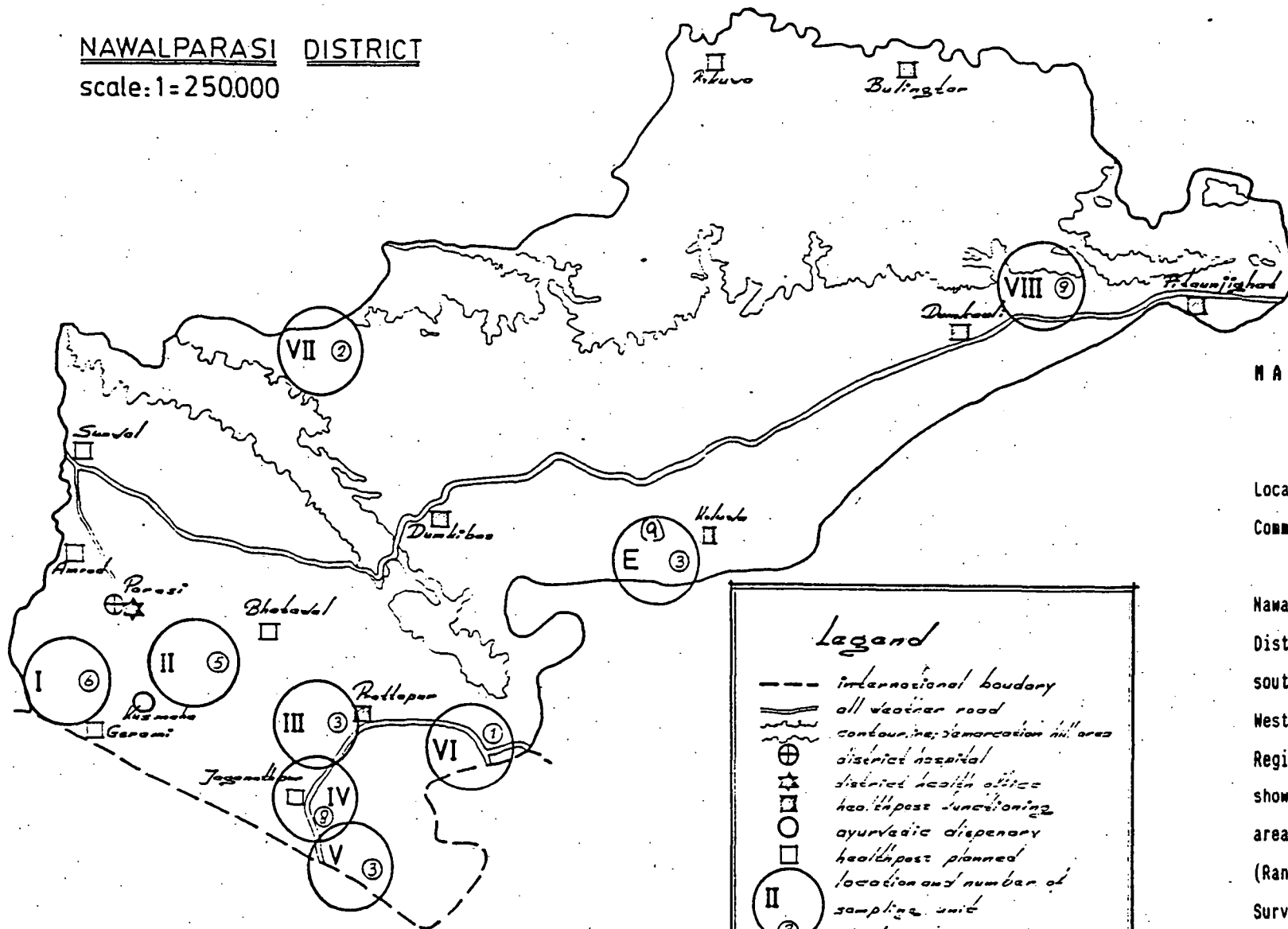
Some implications for health education

Serious thought also needs to be given to use of words and concepts in health education messages about leprosy, as the present approach has taken an exclusive western view. It had said leprosy equals KUSTHAROG and KUSTHAROG is curable. However KUSTHAROG, as reflected in these community findings, means a serious disease with a mixed metaphysical/physical (supernatural/natural) origin and a mental picture of a person with ulcers and deformed hands and feet who must be set apart socially, and who can usually or occasionally, and sometimes never be cured, with a combination of means but predominantly with medicine. It would perhaps be better to aim to add in to this picture the dimensions of early leprosy, perhaps calling it something else, rather than to aim to replace the old picture with a new one. This is discussed in detail in Chapter 11.

The various Nepali words used for leprosy are discussed in detail in Chapter 10. The next Chapter (9) explores the expectation of social separation and another important socio-cultural mechanism of Nepal found to be used by people diagnosed as having leprosy and having significance in relation to clinic attendance.

NAWALPARASI DISTRICT

scale: 1=250000



MAP 7.

Location of
Community Survey:

Nawal Parasi
District in the
southern part of the
Western Development
Region of Nepal:
showing sample
areas.

(Random Sample
Survey Report
1980:Appended)

Legend

- international boundary
- == all weather road
- contour line, 3000m above sea level
- ⊕ district hospital
- ⊕ district health office
- health post functioning
- ayurvedic dispensary
- health post planned
- ⊕ location and number of sampling unit
- ⊕ word number
- Kuluwa name of health institution

TRAVEL DIFFICULTIES



Most patients must
walk over mountain
trails...
(Hyland)



negotiate crowded
buses and...
(MJ Truchanas)



ford swollen rivers
on their way to
clinics.
(Hyland)



TRAVEL DIFFICULTIES

Some patients must
be carried long
distances...
(INF 1971)

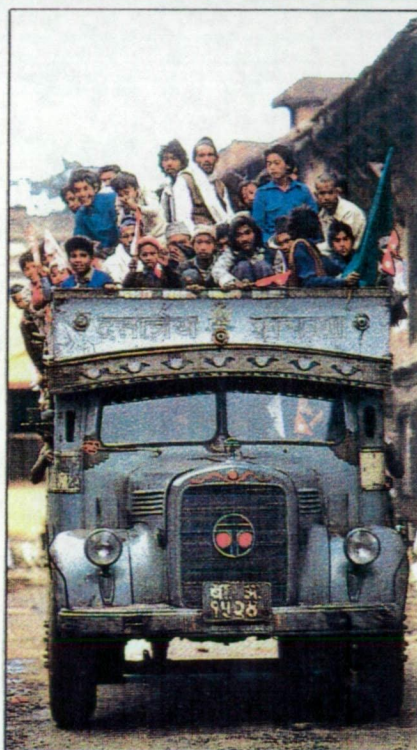


and across
temporary bridges.
(Armington 1979:129)



RESEARCH LOCATION
POKHARA VALLEY

Rural village.
(Hyland)



Travel by vehicle.
(Nepal 1985:175)



Rice ready to
harvest.
(Hyland)



TRANSPORTATION OF
SUPPLIES TO REMOTE
AREAS OF
WESTERN NEPAL

Kali Gandaki Valley

(Nepal 1985:224)

CHAPTER 9: SOCIAL INTEGRATION TO SOCIAL SEPARATION AND "CURE" OF LEPROSY

In the previous chapter the widespread expectation and serious nature of social separation accompanying leprosy in Nepal were noted. This chapter looks more deeply into this aspect of the picture of leprosy. The significance of these findings is discussed in relation to traditional beliefs about illness and cure. The identification of particular social sanctions and safeguards operating generally in Nepal's society, and their application in the case of people with leprosy, throws light on an over-arching reality of life for people with leprosy. This reality may strongly influence their ongoing attendance at clinics for treatment.

The chapter opens with an exploration of the progression from social integration to social separations, an over-arching socio-cultural practice which safeguards ritual purity in the Hindu hierarchic social system in Nepal. This progression exemplifies practices which act as social sanctions to reinforce acceptable behaviour. These practices are seen reflected in social dealings with those who have been identified as leprosy sufferers. The question of "cure" of leprosy in the context of social separation is raised.

The phenomenon of silence, "concealment", private swift action and "exposure" is found in tandem with the progression from social integration to social separation. This is also a general socio-cultural mechanism operating in village Nepal. It is found to be operating in relation to people diagnosed with leprosy. The relationship between "silence" and social integration and of "exposure" and social separation in leprosy is discussed. A likely link between a perceived likelihood of "exposure" and a leprosy patient discontinuing clinic attendance for treatment is identified.

Expectations and Practices of Separation found to be applied to those with leprosy in Nepal in 1990

Community expectations in relation to separation of leprosy in Nepal

What are the community expectations on this matter and what is the possible origin of these expectations? Some of the findings reported in the previous chapter apply here. These were outlined in the last chapter: however, it is of interest to explore any changes in these which may have taken place between the 1980 and 1990 surveys in Nawal Parasi.

Some findings from the community survey in Nawal Parasi are enlightening. There seemed to have been little change in expectations between 1980 and 1990. The matter of social dealing with leprosy is of particular interest here as these dealings seem to be an integral aspect of the picture of compliance behaviour.

In 1980 the matter was dealt with in two sections. Initially the respondents were asked what they would do if a member of their family got leprosy. Would they "separate" them, would they "place them apart" or would they "put them out" of the village? The "separate" and "place apart" options are similar to the 1990 question of "not touching" as they both indicate some degree of ritual pollution and restriction on social interaction within the family, particularly to do with physical contact and handling of food and drinking water. In 1980 46% to 66% would separate or place apart while only 32% said they would put them out of the village. The second time the matter was brought up in 1980 it was in the context of a village person having got leprosy. In this instance 69% said they should be separated and 45% said they should be put out.

The 1990 questions dealt with this matter in a more personal way. The question asked if the fact that leprosy patients are "not touched" and "put out of the village" were reasons for their fearing it. The "not touching" or separation was feared by 79% and the "putting out" aspect of social dealing with leprosy was

feared by 74% of 1990 respondents. The higher percentage found in 1990 probably has more to do with the changed nature of the question rather than representing an actual increase in opinion that this is likely to happen to leprosy patients. This comment is based on conversations with the LCP SES staff, many of whom told me that it was their impression that the social stigma of leprosy was diminishing. The number and seriousness of cases they had to deal with nowadays was less than in the early years of the LCP.

From these responses, it is noted that separation of leprosy patients and even putting them out of the village was, in 1980 and still in 1990, an expectation of over half to almost three quarters of those interviewed. In 1980 respondents were less willing to acknowledge "putting out" as an option when asked about a family member (32%) but in relation to a villager 45% were in favour. As to the less drastic "separation" or "not touching" option 46% to 66% agreed for a family member and 69% for a villager. In 1990, when it came to personal fears of what might be done to them, 79% said they feared "not touching" and 74% feared "putting out". These findings may be closely linked with the ideas of the community that leprosy is contagious (92%), inherited (64%), caused by germs (63%), and causes hands and feet to drop off (83%) as well as relating to the high proportion of patients who linked their condition with the metaphysical.

Separation: Is it an actual experience or just a vague fear for people with leprosy in Nepal in 1990?

Do these replies reflect only vague fears or actual experience and knowledge of social practices in their village or the wider community? Experience gained by the LCP Social and Economic Services staff over the years provides many examples of leprosy patients being actually expelled or put out of their villages. These staff had however gained the impression that these practices may have declined in recent years. There is no way of really knowing how many people with leprosy are separated and expelled. Fewer cases have come to the LCP SES for help in more recent years than were handled in the 1970s and early 1980s.

Even if there is an actual reduction of leprosy patients being expelled, it is clear that the social stigma of leprosy has not disappeared from Nepal as was claimed by some government public health officials in conversation with the researcher in 1990. Findings in this study bear out that there is still stigma associated with leprosy in Nepal. Apart from the public fears and present SES cases, there was a majority of the patients in this study who had experienced separation in some form. The stories of two other people, interviewed as case studies, illustrate the social problems patients face in 1990.

Case Study 1: - "Animal Boy" was a youth from the Terai whose step-mother had put him out of the house and insisted he live in the cattle shed. This lad was medically "cured" in that he had completed all the necessary leprosy medication and been released from control. However he had residual lack of feeling in both hands and feet with disability and deformity which were gradually getting worse. In particular he was subject to repeated ulcers. His family did not regard him as "cured" and according to their expectation he never will be.

Case Study 2: - "Faced with a Dilemma" was a man in his 30s. His village neighbours had come to suspect that he had leprosy and advised (sent) him to the hospital for treatment saying "Come back (only) when you are better." He came as a new patient in 1990, commenced his treatment, was sent home, as is routine, with his month's supply of tablets and instructions to take them daily, to come back in one month for a check-up and medicine. His wife and village neighbours had other ideas. His wife treated him as "untouchable" and not long afterwards took their infant son and left him alone in their poor shack. He did not know where they were. The villagers, upon whom he was dependent for an income as a ploughman, refused to give him work, effectively "putting him out" of the village economically. The SES department attempted to have him reinstated in his village, a task at which they are very skilled. They had not been successful up until the time of my leaving Nepal at the end of the second visit in 1991. The course and progress of his treatment was prolonged and considerably complicated because of

the acute and ongoing psychological distress experienced by this patient.

Both these incidents took place in 1990/91. Social ostracism in relation to leprosy is not just a vague fear but a present reality.

Social integration to social separation: Found to accompany "exposure" of the diagnosis of leprosy in nepal

A progression of "separateness" similar to that discussed below is evident from the data in this study. The experiences of actual patients are further discussed in Chapter 11 where their illness careers illustrate the centrality of the concealment cycle and their compliance behaviour.

Comment on the nature of the data

For the most part the data upon which these observations are based were gathered at a single point of time. It was possible, however, to observe the experience of some of the respondents over a period of up to twenty months. The information, in the main, therefore, represents a snapshot of the person and their situation at the time of interview, with some retrospective details as they told their stories. The people whose stories are represented in the study were therefore gathered when they were at various points in the processes or progression mentioned above. Attempts to suggest possible stages at which people are vulnerable, where they might be or have been at risk of deciding to drop out of treatment remain tentative and await verification through other forms of study in the future. However, as mentioned above, it is clear that there are processes which can be described and associations made. These are put forward here as likely representations of actual socio-cultural mechanisms operating in Nepal in relation to leprosy.

Some patients remained with their families.

There were some who had succeeded in keeping their condition completely concealed and who had been able to maintain their

social integrity, status and security. They were living with their extended family and in the village community.

A few of the respondents had either "separated" themselves or been "separated" by other family members, but remained in the house. In some cases this kind of "separation" seemed to have been sufficient to safeguard their family's position and retained the co-operation of their neighbours for essential times of planting and harvest. This and the following kind of separation are similar to "NACHUNE" or "not touch".

Some patients lived on the fringe of the village in a separate shelter.

The practice of "separation" is taken several steps further in the experience of some of the respondents. After "separation" within the house there may be a separate shelter built and the person required to live there and undertake farm duties to do with the animals, but have no physical contact with the people or household itself. From accounts of patients it appears that this kind of separation seems to have been common in the past in Nepal. The "Animal Boy" above was thus separated.

Expulsion from the village is a further and permanent form of separation experienced by leprosy patients. This level of "separation" is the "putting out". To be expelled is tantamount to being told: "Go and kill yourself!". For example in one case study the interviewee said she had been on her way to "jump in the river" when the leprosy control staff encountered her and brought her to the hospital. In a rural society where the community is inter-dependent, being expelled from the village is a social death. As is discussed below the Legal Code of Nepal used to require leprosy sufferers to be detained in places designated by the authorities, but to be clothed and fed. Through this provision the social death of a person with leprosy resulting from expulsion from his or her family and village in Nepal did not always result in physical death. (One heard a number of anecdotes from staff at the leprosy hospital in

relation to people with leprosy who had either attempted or actually committed suicide following their diagnosis.)

In order to avoid this kind of "separation" some of the study respondents had left their village taking their nuclear families with them to start a new life in another place. Others had actually gone away from their family, from the village, and even from their country (to India) in order to protect the social status of their families. These latter on the whole seem to remain alone.

Some patients are isolated and alone.

After re-examining the data, it is possible to say that a number of the respondents had already passed right through the progression of "separation" and are now living isolated lives away from family and village. Among these were some who had opted to "go away", "withdraw" or stay away for prolonged periods of time, with "legitimate" reasons like employment in India, leaving their extended or nuclear family socially secure.

There were others, like the case study above with a dilemma, who seemed to have had little choice in the matter, who had in effect been "expelled" from their village communities. Some of these were then spoken ill of in the village. The kind of labelling encountered included, for example, womaniser, drunkard, gone mad, gambler.

Of particular interest and significance to this thesis were the last categories of patients, some of whom were found to have started again and others who had stopped attending the clinic.

Those who had started again

There were some who, although they had passed through the process of "separation" from the village, had managed to move with their nuclear family to another place and start again with silence.

Those who stopped treatment

Finally there were some who seemed to have been on the brink of change, on the brink of being "exposed". They seem to have decided to stop their treatment for leprosy rather than risk this "exposure" and the anticipated "separation". This is the "swift action" that they took.

Discussion

A SOCIO-CULTURAL PRACTICE FOR MAINTAINING RITUAL PURITY:

Progression from social integration to social separation

The significance of the "separate" concept will be clarified in the context of its socio-cultural meaning in Nepal. It has to do with ritual purity and impurity in the Hindu system of social interaction as well as with "us" and "them" (Bista, 1991:97).

Separation to do with water and rice

Ritual pollution sometimes resulting in persons being isolated or separated from normal society by the imposition of social sanctions are illustrated from part of the previous Legal Code of Nepal as translated by Macdonald (1984). He published a translation and notes on the section on *The Hierarchy of the Lower Jat* (Castes) as it appeared in the Nepal Legal Code up until 1963. This section deals with the relationships between people of high castes and those of lower castes. Certain activity is prohibited. In general the giving and receiving of water and food are strictly controlled, the higher castes not being permitted to receive food or drink from the hand of lower castes. If they do eat or drink they are ritually polluted and are subject to prescribed sanctions as are the lower caste persons who gave the water or food.

Separation within the household

Women are periodically ritually impure during menstruation or childbirth and "separate" themselves in the household, withdrawing from certain activities and parts of the house, from

physical contact with male members of the household and from objects with which they may come in contact. This kind of "separateness" or isolation is called NACHUNE (untouchable or "not touched").

Separation to do with removal from caste status

In particular the section referred to by Macdonald (1984) deals with ritual pollution and social consequences of prohibited sexual relationships between the higher and lower castes, with the consequent sanctions and punishments and restorative mechanisms. For instance a man of high caste who had sexual relations with a woman "from whom water is not acceptable" in some circumstances would be punished by confiscation of his goods and be condemned to a period of one to one and a half years in prison. As well as that he may have his sacred thread (his caste status) removed, being excluded from his Jat, taking the Jat of the woman. In other circumstances he may have to pay a prescribed fine.

Restoration

The "untouchability" of menstruation and childbirth is brought to an end by the performance or observance of certain routine religious duties and purification ceremonies after the appropriate time lapse. Those polluted through prohibited reception of water or rice are also in need of restoration through purification. Likewise the man polluted through proscribed sexual liaison may have the right to a Certificate of Purification (PATIIYAA PURJI) for a fee after a Ceremony for Re-admission to his caste (PATIIYAA). Then he should have a ceremony of expiation (PRAAYASCIT) performed for him (Macdonald 1984:283 ff).

Separation from village community

Miller (1990) observed an actual village community dealing with an instance of prohibited sexual liaison. What resulted was that the individuals concerned were "expelled" from the village and

sent away to fend for themselves elsewhere. This expulsion from the closely inter-dependent village community could be termed "social death" and in effect says to the individuals concerned, "Go and commit suicide!". For the individuals thus separated there does not appear to be any process for their restoration to that community.

A SOCIO-CULTURAL MECHANISM FOR AVOIDING SOCIAL SANCTIONS: Silence - "Concealment" - Private Action

Village people in rural Nepal guard their privacy in their community by either silence or "concealment". Casper Miller (1990) explains this in his thesis, "Decision-Making in Village Nepal." He refers to the "...lack of privacy (in) village life and the consequent difficulty of keeping anything secret". He states that "keeping silent about matters that are of their nature personal and private is one method, but silence has very limited practicality in a social setting where questions are always being asked". People use words as a shield. He discussed whether or not this should be rendered in English as "deception". He comes to prefer "concealment" as a better rendition of the phenomenon he describes. He found that village people see it as "...necessary to use concealment with those whom experience has shown to be untrustworthy and from whom opposition or manipulation can be expected. Concealment is self-defence". (Miller 1990:145)

In the rural village of Nepal, where there is little if any privacy, the technique of concealment is used to keep to themselves matters which if known to others could be used in their manipulation and to their detriment. Miller suggests three steps in this process. First the matter is not mentioned; silence is maintained. In the event of people becoming curious and asking questions Stories may be invented to divert attention away from the real matter. This is concealment; words are used as a shield. However, when there is imminent danger of the matter being discovered swift action may be undertaken. Miller (1990) presents this structure in relation to decision-making in the village. Here in this study it is seen to be operating in

relation to leprosy and some decisions taken by patients and their families.

In rural communities like Nepal where each person and family relies on others to help them in their fields and so on, harmony is very important and outward conflict usually avoided. Miller mentions that if there comes a time in the village when people begin to talk about a person behind his or her back they keep their face-to-face relationship harmonious. He calls this **Private Slander-Public Silence**.

The "Silence" - "Concealment" - "Private Action" technique found to be used by people diagnosed with leprosy in Nepal in 1990

The pattern of social separation found to be present among people with leprosy reflects that of the wider society in relation to ritual pollution and purity. People with leprosy, aware of the social consequences of their condition being known, make use of the "silence" technique for keeping it private.

This technique is seen to be operating in the case of leprosy as a means of guarding against the application of the separation sanction. Clues to this were found in the interview transcripts. Some of the interviewees said things like: 'They don't say anything';, or 'They started asking questions'; or 'They talk about me'. There appear to be gradual stages of **private curiosity**, then **suspicion**, followed by **gossip** before the **private slander** begins. Eventually, if there is confrontation, the slander comes out into the public arena and the individuals concerned hear it; at this stage they may be confronted. The ensuing conflict may be resolved by the individual being "isolated" or being "expelled" from the village community. In the cases of some with leprosy, those concerned took "private action" before such conflict occurred so as to preserve the social integrity of their family and themselves. They "withdrew" from their village, alone or together with their nuclear family, and set up house in another place.

A process or cycle of application of the technique of protection through concealment can be described from the data. This

concealment cycle is represented in Figure 12:3 and discussed fully in Chapter 12.

"Silence" and Social Integration

It is clear from the data of this study that the fact of having leprosy, or being likely to become a Kustha rogi (a leprosy sufferer), is a matter about which it is very important to keep quiet. Why? Because it is a matter which, if it becomes known to outsiders, could be, and is at times, used to the disadvantage of the individuals and their families. Added to which, if "everybody" knows about it, the persons concerned are expected to be separated in some way from their families and community. Of the people studied, about whose condition "everyone" knows, all but one are "separate" in some way. The matter of self and family protection through silence seems then to be important to most of the respondents.

"Exposure" and Social Separation

In the case of leprosy the process or stages of application of techniques of self and/or family protection through silence and "concealment" are closely linked with and reflected in the living situation of the people concerned. A parallel progression is noted in regard to whether, since the diagnosis, the person with leprosy is still living in the village, with the family or separated in some way or has moved with or apart from the family. There appears to be a very close association between "everyone" knowing about the leprosy and the person being "separated". All but one of the people studied about whose condition "everyone" knows are "separate" in some way. There are a few who are "separate" about whose disease their neighbours may not yet know, but who seem to have "separated" (withdrawn) themselves as an anticipatory or precautionary measure. In the case of the one exception, it may be that she is not "separate" because her husband has a position of influence in the village; on the other hand, it may be that she was concealing her real status from the interviewer. She certainly expressed fear of "expulsion" when refusing certain therapy so it is very likely that she is in

reality "separate" but still within the household. Being on the brink of "everyone" knowing seems to have been a significant factor when it came to some people deciding to discontinue medication.

Practice of separating leprosy from society: Rooted in religious tales, enshrined in law in Nepal and exemplified in the lives of people with leprosy in 1990.

Where do these expectations and practices come from in the Nepal context? The practice of separation and putting out of leprosy patients in Nepal seems to be rooted deep in antiquity. It is reflected in a religious tale, taken up and encoded in the Nepal Legal Code of last century and in part reinforced by world-wide practices of quarantine at the time.

First, the religious tale dates from about 1600 years ago. It is found in a book of tales which has been read aloud in a particular month and recited annually in orthodox Hindu households across Nepal. One of its stories is of a queen on a journey being carried by bearers. They stop to rest in a forest and the bearers wander off to observe and take part in a ceremony of non-earthly beings. After a long time the bearers return to the frustrated and furious queen with some of the sacred offering. She is so angry she throws it to the ground and desecrates it. Calamity strikes and she is struck down as a leper, a curse from the gods, for her sin. After much anguish and bringing calamity on those she comes into contact with she at last learns the way to be rid of her curse. She fulfils the requirements of the religious ceremony. Immediately she is cleansed and made more beautiful than ever, restored to her husband and his court. (See appendix for translation of the full story.)

This story found in the "Swasthani Bradkotha" seems to be a kind of "cautionary tale" which, when heard and repeated by people from infancy, becomes woven into their belief system. When I asked around the town as to whether people saw the events described as "just a story" there was no hesitation in replying

that they really happened. To the people who hear them they are real events.

Secondly, the Nepal Legal Code, enacted at the end of December in 1853 AD, contained certain provisions regarding MAHAROG (the great disease) or leprosy. (These notes are taken from a paper in Nepali presented by Dr Gauri Shankarlal Das to a seminar in Kathmandu in February 1978 titled "Legal Arrangements and provisions for and about KUSTHAROG (leprosy)". The legal code of Nepal, called the MULKI AIN, was applied nation-wide in the reign of Sri Panch Surendra Bikram Shah Dev following the period of over 50 years when Hindu law was gradually applied in the newly unified nation. In it those with MAHAROG were not permitted to enter the city: 'Because MAHAROGI men are not permitted into the city they are to be put outside and provided with food and two sets of clothes per year...by the GUTHI.' Whether this applied to women as well is not clear. Along with this there was a provision for a man to return any betrothal gifts and leave his espoused if the girl was a leprosy sufferer (KUSTHA ROGI).

The MULUKI AIN underwent a major revision in 1886 AD under Sri Panch Prithiwi Bir Bikram Shah Dev. It provided that "...people with MAHAROG were to be placed in a place assigned by the government, given food, clothing by the GUTHI members' decision". In the 1933 AIN, MAHAROGI men were not permitted in the city.

In the 1935 AD AIN, enacted under Sri Panch Tribhuwan Bir Bikram Shah Dev (grandfather of the present king), the provision does not mention the city, merely stating that 'people with MAHAROG are to be put in a place appointed by the government'. In this AIN there is also provision for MAHAROGI (and those blind in both eyes) to be given first place by those in charge of alms. In this AIN there is also provision that if either the girl or boy is found to be MAHAROGI then no wedding tax will be charged. There is a "punishment" that the wedding expenses are to be returned and that the boy may leave the girl. While in the 1853 AD AIN there were different punishments set down for different JATI (castes), the provision in the 1935 AD AIN was the same for all castes.

The 1935 AD AIN was revised under Sri Panch Mahendra Bir Bikram Shah Dev (father of the present king.) and promulgated in 1963 AD. In this version the provision for MAHAROGI people to be sent to a place appointed by the government is still present. It adds that the local Ward Leader or Magistrate is to do this. The people with leprosy are still to have first place in the distribution of free dry food. There is also provision for marriages to be cancelled if arranged for either a boy or girl MAHAROGI if this fact had been concealed. A penalty either way of Rs500/- was to be paid. The husband could leave his MAHAROGI wife and take another.

By 1978 the provision for MAHAROGI to be sent to a place appointed by the government by the Chief District Officer was still present but added to it was "...the place where the MAHAROGI is sent is not to be a place where medicine and treatment is not available".

Nepal community members who expect that people with leprosy will be isolated are reflecting perhaps both the religious belief and the law as it stood in Nepal for over 120 years. The practice of mandatory isolation of leprosy reflected the thinking in many other parts of the world at that time, when isolation was the means used for control of many conditions including leprosy. While it may have provided for protection of the general population as well as the leprosy patients, it was not always applied in a humane way. It seems to me that some of the fear of leprosy may well stem from these factors as much as from the disabling, deforming characteristics of the disease itself. This law was still in force when the INF LCP began in 1974 and its effects linger on in society even after the letter of the law is changed.

In his 1978 paper, Dr Das recommended that the law be changed because "it had become unnecessary and harmful". He said:

It is clear that the aim was to keep leprosy patients in a separate place apart (leprasaria, two of which had been provided) as there was no effective medicine. In the aim the AIN showed inspiration. But one kind of leprosy is not infectious, and leprosy itself is less infectious than other infectious diseases. The AIN, however, had an opposite effect; it "backfired" as far as leprosy control is

concerned. In the AIN provision was made that the police could take and forcibly send a KUSTHAROGI to one of the leprasoria. This means that the diseased were hidden and untreated. According to the AIN the KUSTHAROGI were to be put out of their villages and provided for physically. Current thinking is that KUSTHAROGIS can be treated and remain in their home and families; there is no need to send them to a leprasarium. These days leprosy becomes better through scientific medicines. This means that just as with other infectious diseases a husband cannot marry again so with leprosy also a husband should not be allowed to leave her. The AIN needs revision in this regard.

As a result the MULUKI AIN in force in 1990/91 mentioned leprosy as a ground for marriage annulments only if the fact of leprosy on either side had been hidden by those arranging the marriage.

The cultural adaption time lag

The gradual changes of the law in relation to leprosy in Nepal are not yet reflected in community expectations. Macdonald (1984:281) in speaking of the Legal Code of Nepal and items which had recently been omitted comments "...its prescriptions and its omissions have not yet been incorporated into the customs of the people". The fact that the changes in the law to do with leprosy are not yet being reflected in the culture of the people gives a clue to the irony of the present situation for leprosy patients in Nepal. Scientific medicine has produced effective treatment. The treatment time has been reduced from up to a life-time to a period of from six months to three or so years. New multi drug therapy guards against drug-resistant strains of M. leprae being developed and within a few days renders infectious leprosy non-infectious. From a public health point of view people with leprosy who are on regular treatment can remain in their homes and among their families and communities. But these advances in scientific knowledge, and the programmes put in place implementing policies based on this knowledge, do not yet find an echo in the cultural practices of Nepal. The law in Nepal no longer requires the "leper" to be isolated in a place assigned by the authorities and no longer requires these same authorities to provide food and clothing for those thus socially "separated". What happens to those socially separated now but who are not thus physically sustained?

SOCIAL SEPARATION AND "CURE" OF LEPROSY

Social restoration in leprosy.

As mentioned in Chapter 8, there remains an unanswered question as to whether for people with leprosy who have been separated in any of these ways there is a specific way back into full participation in the family and community. Is there a return to social health, a return to social integration? Is there a cure for social death? Is there a ceremony, an appropriate ritual cleansing, parallel to those which restore the "untouchable" and the sexual transgressor? The answer to this question awaits further research and innovative thinking on the part of all those concerned with leprosy in Nepal. This matter is discussed again in the concluding chapter (12).

Concluding remarks

The finding that socio-cultural mechanisms of control, the application of social sanctions through separation, are operating in Nepal society in relation to leprosy is not new or unexpected. This was well known at the time of implementing the Leprosy Control Programme. Indeed it formed the basis for some of the efforts at public health education of the programme at that time. However the hopes of those education programmes, that such practices would be reduced as a result of the education, have not been fulfilled. Given the deep traditional roots of those practices, it was probably naive to hold such a hope. Those who advocated change to the law also may have cherished such hopes.

The fact that changes to public expectations of social separation of leprosy have not taken place to any marked degree leaves newly diagnosed leprosy patients with few options. The diagnosis must be concealed from those who may use the knowledge to apply social sanctions and thus jeopardise the future welfare of themselves and their family.

What is new from this study is the revealing of the operation of the technique of "concealment" and the construction of the concept of the "Concealment Cycle" in the case of people diagnosed with leprosy. The operation of the "silence" technique is reciprocal to the persistence of the social sanction of separation in Nepal society. This finding is of fundamental importance to those trying to control leprosy, to those concerned about patient non-compliance, to those concerned with public and patient education and to those who wish to shape culturally informed and appropriate health services in Nepal. This is the reality, the world of the individuals in Nepal who have leprosy. The next chapter describes the present shape of the leprosy services they face when they seek help in Pokhara.

CHAPTER 10: HEALTH WORKER EXPLANATIONS, SERVICES STRUCTURES, AND PATIENT RESPONSES

The views, practices and social sanctions of communities in Nepal in relation to leprosy were described in the previous two chapters (8 and 9). The leprosy patients, who are the central focus of this thesis, live in communities like these. When they eventually seek help from the leprosy services, what is the medical system encountered? What is the medical system culture with which people with leprosy are faced? It is a system primarily based on, and limited to, the biomedical definition of leprosy. The services provided are largely fashioned according to and limited by this definition.

In this chapter the views and practices of the health workers who provide care and services for the leprosy patients are reported. The working context of the health workers, and the structure of those services and systems set up for dealing with patients are described. This is the medical system culture to which the new leprosy patient in Nepal relates.

WHAT ARE THE MEANINGS OF THE NEPALI WORDS USED FOR "LEPROSY"?

In order to understand the cultural meanings presented by the health workers and their clients, it is necessary to understand the meaning of words used to refer to leprosy. In Nepal three words are used to refer to "leprosy"; they are MAHAROG, KOR and KUSHTHAROG. Dictionaries tend to give each of these words as synonyms of the others. However, from initial findings of this research it appeared that some people differentiate between them. This was noticed particularly in the community survey. Research assistants reported that some people seemed to associate KUSHTHAROG with skin diseases in general, while they associated KOR with the disabled and deformed picture of the "leper".

MAHAROG. Literally "the great disease". MAHA means "great" and ROG means "disease". This is an old term in Nepal. The word MAHAROG was used in the National Legal Code of Nepal (MULUKI AIN) for leprosy up until the 1970s when it was replaced by

KUSHTHAROG. It is regarded by some as being associated with PAP, or "sin" - "great" sin leads to the "great" disease. It also contains a sense of moral judgement, the diseased person being culpable. The Turner's Dictionary (1931 & 1980) gives the meaning of MAHAROG as SETO KOR or "white" KOR.

KOR. This is also an old word in Nepal. It is used to indicate a person with disability and deformity from leprosy. It contains an element of condemnation or social judgment passed on the person involved who is regarded as socially unacceptable. KOR is also used in abusive language: "May you be struck down as a leper!". In this thesis the term KOR is taken to be very near to the English term "leper".

KUSHTHAROG. Literally "the disease of rotting flesh". Turner's Dictionary gives "leprosy" as the meaning. KUSHTHA is an ancient term. "According to Vagbhata (600 AD) the name KUSHTHA was derived from KUSHNATE which means "eating away" in Sanskrit", and was mentioned in the Sushruta Samhita, written in India in about 600 BC (Thangaraj and Yawalkar, 1987:14). However its use is relatively new to Nepal. As mentioned above, it was introduced to the National Legal Code in the 1970s and used in official government documents to do with leprosy control at the same time. It is the name now officially given to "leprosy" by the Ministry of Health and in health education messages about leprosy in Nepal. In the Saral Nepali Shabda Kosh (2045 BS) KOR and MAHAROG are given as synonyms of KUSHTHA. (The prefix KU denotes badness or inferiority in the Nepali language.) These words are further defined and discussed in the following section.

HEALTH WORKER VIEWS AND PRACTICES IN RELATION TO LEPROSY

These are derived from written questionnaires and informal follow-up interviews. Senior health workers from both the field programme and the hospital were interviewed. They were fourteen Nepali leprosy control field workers, ten Nepali and seven expatriate hospital staff.

Nepali and expatriate staff of Green Pastures Leprosy Hospital were surveyed by written questionnaire. The following questions sought insights into their definitions of leprosy.

1. Before you came to work here what sort of disease did you think leprosy was?
2. What changes occurred in your thinking about leprosy after you had worked here some time?
3. How would you describe leprosy, what kind of a disease is it?
4. In your thinking does leprosy sometimes not get better?
5. What are the duties of a "leper"?
6. What is a "leper"? Describe.

Responses to these questions provide material for describing the medical system culture encountered by the leprosy patients, under study in Nepal, both in the field and at the hospital. Notes made during visits to clinics and observation of encounters between health workers and patients are drawn upon as they illustrate particular aspects of the picture.

Senior Nepali leprosy control field workers

The 14 respondents had experience in leprosy ranging from one to 17 years (average 10.7 years). In a short written questionnaire they were asked for their opinions about the understanding of the community as well as for their own definitions of these terms.

The questions were:

1. Do people in your area understand the terms Kushtharog and Kor to mean the same?
2. Do people in your area understand the terms 'leprosy' and Kushtharog to be the same?
3. Do people in your area understand the terms 'leprosy' and Kor to be the same?
4. In your opinion is:
Leprosy the same as Maharog?
Leprosy the same as Kor?
Leprosy the same as Kushtharog?
Maharog the same as Kor?
Maharog the same as Kushtharog?
Kushtharog the same as Kor?
Kushtharog the same as 'leprosy'?
5. What is the meaning of the term Kor to the people in your area?
6. What is the meaning of the term Kushtharog to the people in your area?
7. What is the meaning of the term 'leprosy' to the people in your area?

Health worker explanations of leprosy

Health worker responses to questionnaires are the basis for this presentation. Findings from the two questions on the understanding related to a "leper" or, in Nepali "Kori," are presented first.

Senior Nepali leprosy control field staff responses

To the questions about meanings of terms for leprosy the following responses were received:

What is the meaning of the term KOR to the people in your area?

This question produced a range of replies: disability, deformity, loss of digits, a curse from god, because of sin, hereditary and infectious were mentioned. In other words, the secondary damage or last stages of disease are associated with KUSTHAROG. A brief mention was made of "educated" people calling it curable and saying it is caused by a bacillus. One stated that he thinks it is a disease like any other.

What is the meaning of the term KUSHTHAROG to the people in your area?

This question produced a similar range of responses such as: disability, deformity, ulcerated hands and feet, infectious and incurability.

"The same as KOR." "It is a disease of hands and feet cured by medicine." "Anaesthetic skin patches with weakness of the hands and feet." "A disease like other diseases." "Those who have some knowledge of "leprosy" call it "KUSHTHAROG".

What is the meaning of the term "leprosy" to people in your area?

There is a somewhat different range of response to this question. They consider that most people do not know this word. To those who do know it, it is a skin disease and KUSHTHAROG.

"Ten years ago people thought leprosy was hereditary and coming from PAP, sin, not curable, and infectious." "In remote areas they think that drugs are not available for it." "Nowadays they think it is a chronic skin disease caused by bacteria." "Some think it is an early stage of a skin disease with light anaesthetic skin patches, which, when medicine is taken does not infect anyone."

One enlightening response indicated that some people think it is a type of family planning, "leprosy" = "laparoscopy"!

It is noted that these respondents tend to associate Kor with the late stages of disease, "late cases" who have deformity and so on, and that they only associate early signs of leprosy with "leprosy" and KUSTHAROG.

The following table sets out the definitions given by senior Nepali field staff (their opinions of community understanding) of the various Nepali and English terms used for leprosy in Nepal.

TABLE 10:1

| <u>Kor</u> | <u>Kushtharog</u> | 'Leprosy' |
|--|---|---|
| <u>Maharog, Kushtharog</u> 'leprosy' (4) a term used by village people | <u>Kor</u> by uneducated/rural (2) 'Leprosy' a term used by educated urban people | <u>Kushtharog</u> by educated (3) |
| <u>Kushtharog</u> with ulcers on hands and feet Deformity/disability | disability/deforming disease disease gives the deformity ulcerated hands & feet (8) | |
| ulcerated hands and feet loss of digits (10) no fingers and toes | | most people do not know this English word (7) |
| infectious | infectious (4) | infectious |
| hereditary | | hereditary |
| curse of god | | |
| because of sin | | from sin |
| not getting better even after long treatment | incurable (2) (poisonous) | incurable |
| no medicines - incurable (2) | | |
| secondary damage- last stage of disease | anaesthetic skin patches, weakness of hands and feet (3) | chronic infectious disease caused by bacilli digits of hands and feet 'fall off' |
| educated people call it curable and caused by bacillus | disease of hands and feet cured by medicine (2) | caused by bacteria early stage of a skin disease with light an- aesthetic patches which when medicines are taken is not infectious |
| a disease like other diseases | a disease like other diseases | |

Further light is shed on this matter from the health workers who were asked a series of "Yes", "No", "Don't know", questions about their own and community understanding opinions relating leprosy, KUSHTHAROG, KOR and MAHAROG. Their responses are discussed following the summary in Table 10:2.

More health workers thought urban people see the terms KUSHTHAROG and KOR as meaning the same than thought rural people do see the terms as the same.

Again more thought urban people understood the terms "Leprosy" and KUSHTHAROG to be the same and that rural people do.

Their opinion of urban and rural understanding of the terms "Leprosy" and KOR as being the same reflects a similar division.

TABLE 10:2

SUMMARY OF OPINIONS OF HEALTH WORKERS AS TO WHETHER CERTAIN TERMS USED FOR LEPROSY MEAN THE SAME AS OTHER TERMS IN NEPAL

| Question: | Reply: HW own & Opinion of Urban & Rural views | | | | | | | | |
|---|--|----|----|-----|----|----|-----|----|----|
| | Yes | No | DK | Yes | No | DK | Yes | No | DK |
| Is | | | | | | | | | |
| <u>Leprosy</u> the same as <u>Kor</u> ? | 12 | 2 | 0 | 8 | 5 | 1 | 2 | 12 | 0 |
| <u>Kushtharog</u> " " <u>Kor</u> ? | 13 | 1 | 0 | 13 | 1 | 0 | 10 | 4 | 0 |
| <u>Leprosy</u> " " <u>Kushtharog</u> ? | 14 | 0 | 0 | 10 | 4 | 0 | 1 | 13 | 0 |
| <u>Maharog</u> " " " <u>Kor</u> ? | 9 | 4 | 1 | | | | | | |
| <u>Maharog</u> " " <u>Kushtharog</u> ? | 9 | 4 | 1 | | | | | | |
| <u>Leprosy</u> " " " <u>Maharog</u> ? | 8 | 6 | 0 | | | | | | |

Discussion

The respondents made a differentiation between urban and rural, probably between "educated" and "uneducated people", assuming that urban people are more likely to be educated than rural people and that the English term "leprosy" and relatively new term "KUSTHAROG" are more familiar to urban dwellers.

[NOTE. The assumption that those in urban areas are better educated than rural dwellers in Nepal is borne out by national statistics of literacy rates. For example, the District of Lalitpur, in which the large urban area of Patan is located, has a literacy rate of 37% while the District of Dhading, which is almost entirely rural, has a literacy rate of only 15%. Another example: the District of Kaski, where Pokhara is located, has a literacy rate of 34.5% while Myagdi, which is almost entirely rural, has a rate of 22% only. Calculated from figures given in the Statistical Year Book of Nepal, 1989, HMG/N:18ff.]

Whether all the differences in the replies to do with leprosy, "KUSHTHAROG" and "KOR" are to do with the likelihood of the

terms themselves being well known to urban and rural people or whether there is an actual difference between the terms themselves is not very clear from these responses. Ten (71%) of the field workers think urban people regard "leprosy" and KUSHTHAROG to be the same while only eight (57%) think urban people regard "leprosy" and KOR to be the same. While these are only opinions and they probably reflect health workers' belief that they themselves are better educated in these matters than the general community about whom they speak, they have been borne out in conversations with other field workers.

Some disagreement appears between these field workers about *their own definitions* of the terms.

They *all agreed* that "leprosy" = KUSHTHAROG (14/14 - 100%); *most* (13/14 - 93%) thought that KOR = KUSHTHAROG; *most also* that "leprosy" = KOR (12/14 - 85%); *fewer* were sure that KUSHTHAROG = MAHAROG (9/14 - 64%); or that KOR = MAHAROG (9/14 - 64%); and *even fewer* thought 'Leprosy' = MAHAROG (8/14 - 57%).

Logically, if "leprosy" = KUSHTHAROG and KUSHTHAROG = KOR then KOR = "leprosy". Among these workers there was not unanimous agreement on this proposition.

If there is a difference it is interesting to speculate as to whether this might have to do with the strong negative connotation attaching to KOR?

When it came to expressing *their own opinions* an attempt was made to find out if *they* were seeing a difference between "leprosy" with a narrow biomedical definition and "KUSHTHAROG" with an association with physical deformity and broader social meaning. The answers given seem to indicate that most of them had adopted the new, modern teaching and so had narrowed their definition of "KUSHTHAROG". One could speculate further that the health education programme of the Leprosy Control Programme has been successful, in that to these health workers at least, the Nepali term "KUSHTHAROG" has now been given the more narrow "scientific" definition of "leprosy". Whether this outcome, upon reflection, is a desirable one is food for thought as the findings of this research are laid out and their implications discussed.

These responses are after all only from 14 people and are only opinion. They may, however, be indicative of some semantic difference. The opinions of other Nepali staff seem to clarify this point.

Nepali leprosy hospital staff responses

Responses to this question reveal some differences from those of the expatriate staff. The responses of the Nepali staff are to this question in Nepali where the word KOR was used for "leper". Here are some of the responses:

Descriptions of a "KORI" (a "leper" or one who has KOR)

"According to "old" thinking leprosy used to be called "KOR", but now (implied) "KOR" is "KUSHTHAROG". "There is a custom to call a leprosy patient "KORI". "A leprosy patient is "KORI" if they have visible deformity and disability." "KORI" is a word which is used in society to abuse useless people, it is used of those who cannot remain in society, for example, people with no hands and feet cannot do anything (work) so it is used of leprosy patients. Through the word "KORI" it is signalled that the person has been rendered "pitiful" by leprosy." "Immediately upon hearing the word "KOR" one sees the picture of a person with deformed nose, eyes, and feet." "It used to be the practice in the days of Nepal's ignorance to call people with leprosy "KOR" and to isolate them."

Duties of a "KORI" ("leper")

Some of the respondents seem to want to divide the topic between "then" and "now". However, in reality the actual present situation in Nepal, as experienced by some deformed people with leprosy, is what the respondents want to call "then". Several of the interviews with patients presented in following chapters bear this out.

Here are some of the responses of Nepali staff.

"Through the "blind" beliefs of our society the "KORI" was placed far from the community, near a river or the jungle (public isolation). His village community and family were

supposed to but could not feed him. Instead they used to say: 'Go and stay anywhere you can!'" (public expulsion). "Before, the duties of a "KORI" were to survive from begging, to stay far away from main roads, villages and towns, to let people know if they were approaching him."

"Now the duties of a "KORI" are to care for their own body, to work as they are able, to maintain their place in society, to take medicine and to advise neighbours and family members to seek to be examined regularly and if any have got leprosy to seek treatment immediately."

Expatriate leprosy hospital staff responses

These responses are from health professionals from England, Germany and the United States of America. There were two doctors, both of whom did leprosy surgery; two nursing sisters; one of whom specialised in eye care; one laboratory technician; one orthotist, who dealt with footwear and artificial limbs; and finally one occupational therapist. Their working experience was from 18 months to six and a half years, average four years. These questions: "*What is a "leper"? Describe.*" and "*What are the duties of a "leper"?*" again yielded expected answers. They reveal the background idea of social ostracism and add in a social comment in the context of Nepal about begging.

A "leper" is a physically deformed person suffering from leprosy, often with suppurating wounds, who is socially stigmatised because of the physical deformities, outcast from normal society, looked down on, feared and who depends on other people for his living.

According to the expatriate doctors and nurses, the duties of a "leper" are "to keep out of the way, to separate himself from his village and family", "not to make anyone else unclean", and "to be subject to charity so that others can gain benefit from giving alms". One person went as far as suggesting that a "leper" is expected "to commit suicide". This suggestion is not as gross as it may sound. One sometimes heard of patients who had reacted to the news of their diagnosis by attempting to actually do just that. The year before this study was carried out one teenage girl had committed suicide upon being admitted to Green Pastures Hospital. One of the patients interviewed in

this study was on her way to "jump in the river" when she encountered the leprosy programme and was brought to the hospital.

What sort of disease is leprosy?

Having dealt with the meaning of "KOR" and other terms for leprosy used by people in Nepal (in the opinion of experienced leprosy field workers), the responses of the staff of the Green Pastures Leprosy Hospital on the nature of leprosy are taken up. The responses of Nepali and expatriate staff to this topic are presented and discussed in this section.

Nepali leprosy hospital staff responses

Nepali staff reported *initial definitions of leprosy* as "a feared, infectious, dangerous, hereditary, incurable, "big", very furious disease"; those suffering from which "should be removed from the community", evoked very negative thinking and was "a disease which gave one the chance to laugh at an enemy" and was "caused by a curse and sin". Some reported either ignorance or neutral feelings. Some had prior knowledge which left them with positive feelings towards patients.

The *changes that have taken place in their thinking about leprosy* were mainly to do with gaining understanding and changed outlook. Knowledge has been gained as to how deformities occur, how leprosy happens and that it is only mildly infectious, not very infectious. As well as that, getting to know people with leprosy and seeing their circumstances has led to change in attitude to positive from negative.

The Nepali staff gave the impression of having strongly adopted the "biomedical" explanation of leprosy. Some also expressed an appreciation of the "mental" and "social" effects of leprosy. The strength of their 'bio-medical' response may be because it is actually their prevailing belief, or it may be that some have given the responses they think their old teacher wanted!

A present definition of leprosy built from the Nepali staff questionnaire responses.

"Leprosy is a common or ordinary disease caused by *M. leprae*."

"Leprosy is an ancient disease caused by germs."

"Leprosy is a disease of humans which comes slowly and gets better slowly." "It affects the skin and nerves." "There are six types, two are infectious and four non-infectious, but they are all non-infectious if the patient is taking medicine." "The infectious type is bad disease." "It is infectious only after a long period of time." "It can be caught by people who have no immunity." "This disease will get better with regular treatment." "It is easy and cheap to treat." "Treatment can be taken staying at home, and leading a normal life in the community." "If patients take care of themselves deformity can be stopped if treatment is on time."

"Leprosy is a disease specially of the poor and it is inherited."

"Leprosy is a physical disease but is so much linked with social and mental things." "When I see their mental situation I want to be kind to them." "Diseased persons can be picked out (recognized) among others." "Because of community attitude the disease affects more mentally than physically." "I feel there is deep pain of imbalance in social and mental things." "The law's restrictions should be removed."

Leprosy "falls among diseases which need political, social, economic and mental support along with treatment."

In short leprosy is "a chronic, mildly infectious physical and social disease."

Those who take the explanation further than the physical mentioned points like:

"...there needs to be community awareness...the law's restrictions...because of community attitude this affects patients mentally more than physically"; "...deep pain of imbalance in social and mental things"; "...linked with social and mental things"; "...need for political, social, emotional and mental support..."; "it is a ... social disease."

Nepali staff may have adopted these views as a result of evidence - repeated reminders of the social and psychological effects of leprosy on the patients they dealt with. They may result from personal life experience. Two of the respondents were ex-leprosy patients. It may perhaps have resulted from working with and having discussions with the researcher. Whatever the source some respondents had made attempts to expand the usual biomedical definition of leprosy to include the social implications and spoke of a need for the kind of support which could counteract or address the social ostracism of leprosy and which is as yet not usually found in the treatment regimens.

Expatriate staff responses

The first question, *"Before you came to work here what sort of disease did you think leprosy was?"* yielded the expected scientific, biomedical notion of leprosy, represented by Jopling's definition:

Leprosy (Hansen's disease (HD); Hanseniasis) is a chronic mycobacterial disease (infectious in some cases), primarily affecting the peripheral nervous system and secondarily involving skin and certain other tissues. (1984:1)

One respondent included the social consequences of leprosy by saying that it makes "outcasts of people".

The second question was *What changes occurred in your thinking about leprosy after you had worked here some time?* There had been some change in their thinking about leprosy since commencing work at Green Pastures. One of the doctors learned that "paralysis due to inflammation of nerves really does get better if treated early and well enough". There was a realisation that "it is less infectious than I thought", added to the realisation of the "importance of the psycho-social dimensions in managing patients (clinically) and the political dimension of controlling it". The nurses were also pushing out the boundaries of their definition. One mentioned "the social and emotional implications of the disease" as a "bigger problem than the medical and surgical treatment".

From the replies to the third question, *"How would you describe leprosy, what kind of disease is it?"*, a description or definition of leprosy was formulated.

Leprosy is a chronic mildly infectious disease, caused by M. leprae, causing damage to the nerves and skin. This may result in anaesthesia, and paralysis with subsequent inevitable disability and deformity.

Leprosy is a disease, the microbial aspects of which are curable under certain conditions, while its deforming consequences are not always amenable to medical treatment with present methods and knowledge. Some deformity however can subsequently be corrected.

Leprosy is a fascinating immunologists' "dream disease".

While leprosy is seen as a disease caused by a mycobacterium having potentially serious and progressive physical consequences it is also seen as a disease with considerable social and psychological effects. The implications of these at times

outweigh the medical and surgical in magnitude.

Leprosy is a disease which for some patients results in their being obviously physically disfigured, consequently being socially stigmatised, obliged to live separately (ostracised) and resorting to begging.

In short leprosy is a contagious and disfiguring disease making outcasts of people.

All expatriate respondents based their definition on the "germ theory" of causality of leprosy making infection the starting point. This is consistent with textbook definitions. Some limited their definitions to the biomedical (physical) effects of the condition.

However two or three of the more experienced expatriates expanded the scope of their concept of leprosy to embrace the *psychological, sociological and even political effects and implications of the disease*. On the part of these respondents there seems to be a struggling with, and a hesitant desire to expand the definition with phrases such as:

"social and emotional effects and implications are bigger than medical..."; "the social side of leprosy is a vast problem as their psychological effects..."; "psycho-social dimensions ... political dimensions...".

These were used by several people when discussing the changes to their thinking that had taken place since starting work with leprosy patients. One person even ventured to expand the present definition itself.

*"I would like to define it further than a chronic mycobacterial disease, in that it is just as importantly a **sociological disease**. Chronic stigma can be even more destructive."*

Further thought needs to be given to the implications for leprosy care services and for education programmes of acceptance of such a broad definition of leprosy. What would it mean for the notion of cure for instance? What about cure of the social disease? These questions are re-visited in Chapter 12.

Is Leprosy Curable? This question is answered by field and hospital and expatriate staff.

TABLE 10:3

NEPALI LEPROSY CONTROL FIELD WORKERS ANSWERED THE QUESTIONS:

| | Yes | No | DK |
|--|-----|----|----|
| Do the people in your area: | | | |
| Believe <i>Kor</i> to be curable? | 4 | 10 | 0 |
| Believe <i>Kushtharog</i> to be curable? | 6 | 8 | 0 |
| Believe "leprosy" to be curable? | 9 | 4 | 0 |

The reasons given for doubts about curability are that after treatment is finished, in other words, after it is "cured", numbness, deformity and ulcers sometimes persist.

The leprosy hospital staff gave the following personal responses to a similar question -

Nepali hospital staff gave their personal responses

The responses are best summed up in the words of one person. "At times it is difficult to get better, like when drug-resistant (bacteria) are present or when medicine is taken irregularly." One person seems to have obliquely expressed some doubt when he said: "Some patients used to have to take medicine for their life-time. Nowadays *they say* leprosy is curable." The expression "*they say*" appeared in the community responses and appears again when patient interviews are analysed; usually expressed in the form; "*they say, but...*", indicating some scepticism or doubt.

It seems then that some of the expatriate staff have begun to wonder about leprosy and what it is - whether it is more than the biological explanation allows for and because of this whether it can be said to be curable. The Nepali staff seem to be more categorical in their replies (perhaps this reflects a more recent "conversion" to "modern" medical ideas on their part) except that a hint of a doubt crept in. The question of what leprosy is seen to be and whether this is curable is a crucial one for the programmes to face and clarify, otherwise educational messages are ambiguous and for some hardly credible. This is further discussed in Chapter 12.

This difficulty with the idea of leprosy curability is illustrated from two patient case studies. The first patient has been taking medicine regularly since his diagnosis; however he can truthfully say: *"My physical condition is worse now than at the beginning. Why is this so? I have gone on taking the medicine according to instructions."* He has leprosy. Is his disease getting better? Is he getting better himself? The answer to both questions is "No" because he has had repeated episodes of severe reaction which have not been controllable and he is becoming progressively more disabled. Once he has completed the required period of treatment and is told he is "cured" (his smears no longer show M. leprae) he will be permanently disabled and socially separated.

The second case study is a man who as a patient has been an inmate of the Malunga (leprosarium) for 25 years. He had been present when leprosy treatment was first made available to the patients there some years before. They heard the message "leprosy is curable" for the first time. They waited to see. As they watched and observed they did not see *"the budding again of previously lost fingers and toes"*. They expected "leprosy" as they understood it to get better but it did not. To these people leprosy means the total, all of what happens to the person, his body, his mind and his social relationships.

Expatriate staff responses

Is leprosy curable? (In your thinking does leprosy sometimes not get better?)

In expatriate responses to this question ambivalence is again in evidence. Most are firm in their opinion that if leprosy is not getting better patients are not taking the treatment properly. These seem to hold firmly to the infective, biomedical model. A few allow the thought that if the definition is broader than what they sometimes observe at the hospital can be accounted for by saying:

"Patients' condition sometimes does not get better, the reason, reactions don't always respond as we would like..."; "It appears so if one looks at deformity..."; "Even if the 'disease' is cured, residual anaesthesia leads to continued deformity ... sometimes anyway ..."; "The infection can be stopped but effects on nerves and consequent deformity may not be totally stopped".

These respondents, who seem ambiguous towards the message, "leprosy is curable", do however remain firmly within the *physical* realm when making these statements. None of them venture into the *psychological, social or political* arena.

Discussion

Does it matter that there are differences in definitions of leprosy and "leper" and so on?

Is there a 'true' definition? Does it matter that there are differences? What do differences in definitions say about patient support and health education? Are there aspects of "true" definitions which are essential to "get across" to patients in health education, and to the public in information campaigns in a form they can understand and accept. Are there aspects of patient and community definitions which are essential to "get across" to health workers and service planners? Do any aspects of present services need to be re-thought? My evidence suggests they do. It becomes clear that any message of cure for leprosy needs to address the fact of the changes in their social status experienced by people with leprosy and seek for possible avenues for permanent cure of the social as well as the physical condition.

It is important to consider the implications of definitions because the shaping and style of delivery of services for leprosy control, department divisions, and so on emerge out of the definition of the problem. These are considered in the concluding chapter (12).

LEPROSY HEALTH-CARE SYSTEMS AND PATIENT RESPONSES

What is the medical system culture with which patients are met at the leprosy hospital and in the control services? What are the clinics and the processes through which patients are expected to pass? This section describes and discusses the services and systems set up to provide treatment for leprosy patients. The clinic at Green Pastures Hospital and the mobile clinic are described.

The Green Pastures Leprosy Hospital (GP) is set up to cater for over one hundred in-patients (IPt). Some of the departments providing care for these patients are shared with the out-patients (OPt). The services provided for out-patient are based mainly in hospital departments. These are the laboratory, physiotherapy, medical and nursing departments orthopaedic workshop and operating room as well as the out-patient department itself. There is another department located at the hospital but administratively part of the Leprosy Control Programme - the Department of Social and Economic Services.

The Laboratory (Lab.) does leprosy split-skin smears and blood, urine and stool microscopy as well as some other analyses. The skin smears assist in initial diagnosis of the Mycobacterial disease as well as in monitoring clinical progress on the leprosy therapy. The other functions are mainly to assess and monitor patient general condition.

The Physiotherapy Department (Physio.) carries out routine sensation and muscle strength testing and recording. Again this can assist in diagnosis but is primarily for monitoring clinical progress. This department also conducts regular group and individual exercise classes for patients who have muscle weakness or paralysis.

The Medical Department (Med.) provides referral services of a doctor trained in scientific medicine for any patients whose condition is serious and beyond the scope of training and ability of the Out-Patient Department paramedical workers.

The Nursing Department (Nur.) primarily provides nursing care for the in-patients. But as part of their duties they also give out the prescribed medicines to all out-patients. They also do any necessary dressings or injections for out-patients.

The Orthopaedic Workshop (Ortho.) is where patients who need it are provided with protective or made-to-measure footwear. Those whose feet have lost sensation and are therefore vulnerable to injury, others suffering periodic injury or with deformed feet, and those who have had some part amputated are catered for.

Patients who need some service from the Operating Room (OR) are usually admitted to the hospital but occasionally a minor operative procedure may be carried out on an out-patient.

The Out-Patient's Department (OPD) provides for registration and follow-up of patients as well as their interview, physical examination, completion and storage of patient medical records. Finally, the Social and Economic Services Department (SES) is set up to deal, to some extent, with problems patients have of an economic or social nature.

What is expected of patients when they encounter this system?

The following description is constructed after conversation with the OPD health workers and the staff of each of the departments concerned. They were all asked what was expected of, and what happened to patients as they passed through the process, particularly on their first visit to the clinic.

A new patient's first visit to the clinic

Having arrived at the hospital and found the verandah where the registration window and waiting-area are located, this person is registered as a patient. This involves being questioned by a clerk for the reason for coming, and the nature of that individual's problem. This clerk, as organisational gatekeeper, may suggest that a person does not need the services provided by this hospital if he thinks the person may not have leprosy. (Unfortunately, because the clerk has no formal training about leprosy he may not always be right.) The person's name and particulars are recorded by the Records Clerk and the new patient is given a card and asked to wait to be called to see the health worker in the OPD clinic. The new person visits the following departments in approximately this order:

1. the OPD clinic - for examination and diagnosis;
2. the Laboratory - for smear and blood to be taken for testing;
3. the Physiotherapy Department for sensation and voluntary muscle testing and charting OR return to the OPD for history to be taken;
4. return to the OPD for (history to be taken) clinical examination and charting, classification of the type of leprosy, health education and prescription of appropriate therapy;
5. finally to the Nursing Station where medicines are given out.

Other services may be added, depending on the individual patient's physical condition. For example, if he or she has anaesthetic feet that person will need to visit the Ortho., or for some social or economic problem the patient may visit the SES department as well.

The Mobile Clinic

The mobile clinic has no fixed building. It is a team of health workers, with their equipment and records, which travels by vehicle from place to place on a routine schedule. Clinics are held once a month in each of seventeen places on the route in the Western Region of Nepal. The clinic is set up at HMG/N health posts or hospitals and the people who attend are seen. The clinic is organised and the people expected to pass through the following process, moving from one place and health worker to another.

1. The registration clerk asks about the problem, where the person came from and so on. The details are recorded and a card is issued.
2. The health worker takes a history and does a physical examination. The diagnosis is made and medication prescribed. If there is indication of inflammation of nerves being present the patient may be asked to return after being assessed by the physiotherapist so that additional medication can be prescribed. Some individuals may be given a letter and told they need to go to the hospital in Pokhara because of some acute medical or surgical problem found by the health worker. The person is then instructed to move to the next person on the list and to return on a particular day next month or the month after for the next lot of tablets.
3. The physiotherapist assesses and records the sensation and strength of hands and feet (and eyelids). If the person is found to have anaesthesia of the feet he or she is instructed to wear some sort of shoes. A physio may give the person a pair of canvas shoes or have a measurement taken for a personalised pair to be made at the GP Ortho workshop. These would be ready to be collected by the person at the next visit.

4. The smear technician pinches and cuts the person on at least four routine sites on the body and takes a skin smear. These smears are labelled and taken to GP Lab. to be read. The results are available on the person's next visit. The person leaves this worker with little wisps of cotton wool dressing over each cut.

5. The pharmacist hands out medicines which have been prescribed by the health worker and gives instructions on how and when they are to be taken or used.

6. The dresser treats any ulcers or wounds and applies dressings and bandages if necessary.

All the people (patients) who are diagnosed as having leprosy are expected to return regularly to the clinic to be examined, and to receive the next batch of medicines. They may be asked to return each month or each second month depending on how serious their condition is and how far they have to travel. In some cases they may be asked to return each week or even more frequently for a short period of time if they need particular medication or treatment and cannot actually stay as in-patients. The reason for frequent visits is for their clinical progress to be monitored and so that any "complications" may be diagnosed early enough to effectively treat them, in an effort to prevent disabilities.

Definition of leprosy implicit in the service structure

These listed services and expectations reflect or indicate an underlying definition of the problem of leprosy such as the following: *"Leprosy is a mycobacterial disease (Lab.), primarily affecting the skin (OPD charting and Lab. smears) and nerves (OPD charting and Physio. sensation and muscle testing), curable if treated adequately (Nur. medicines and repeated clinic visits for required length of time), sometimes causing disabilities which are preventable if the condition is diagnosed early and managed adequately (OPD repeated visits, Med., Physio., In-Patient, Nursing), and for some people results in socio-economic problems (SES). At Green Pastures the SES department services are extra to provisions that are standard elsewhere across Nepal. This definition is broader than the one basic to the*

structuring of services elsewhere in Nepal; it does include a socio-economic dimension but does not deal with the psychological and the full socio-cultural implications of the Nepali community definition of leprosy.

Inadequacy of a biomedical definition of leprosy for Nepal

The biomedical model...leaves no room within its framework for the social, psychological, and behavioural dimensions of illness (Engel, 1977).

A comprehensive as well as accurate definition of disease is of fundamental importance to clinicians, public health professionals and health educators alike. The definition of the medical problem being dealt with is the spring out of which flow remedies and health care services designed to deliver those remedies. Researchers and clinicians such as Eisenberg and Kleinman (1981) over recent years have pointed out the limitations of the scientific model of *disease* to provide an adequate frame for explanation of *sickness* and *illness*. Neither the specialist definitions of *disease* nor the patient's experiences of *illness* are alone adequate. Similar limitations are encountered in Nepal when it comes to defining leprosy. Through the canvassing of the Nepali and expatriate hospital staff an impression is gained that some are wanting a more socially adequate, a broader, more comprehensive, definition of leprosy. Consideration of leprosy in Nepal of necessity does not finish with the physical but also enters the realm of the psychological, the social and cultural dimensions, the whole world of Nepali people.

What are the views, expectations and experiences of leprosy patients themselves as they encounter the leprosy services medical system in Nepal? Why do they decide to continue or discontinue the required repeated clinic visits? The fulfilment of the health worker's expectations that they will make regular and repeated visits to the clinic is taken as a crude measure of compliance and hence at least a partial adherence to the belief in 'cure' and the capacity of western

medicine to effect that cure. Is discontinuation of clinic attendance a sign of rejection or response to the "pull" of traditional forces? The following section presents and discusses the experiences of people with leprosy, findings from patient interviews, and Chapter 12 draws the threads together, pointing out associations with compliance.

New patients encounter the leprosy service and health workers

What is the experience of people who hold the notions detailed in Chapter 8 when they meet the health workers and pass through the leprosy services systems which are set up based upon other concepts?

The process through which the patients are expected to pass was detailed in the previous chapter. Prior to beginning patient interviews, the researcher and assistant repeatedly walked and talked round this 'route' as part of the field work observation, holding conversations with the staff in each department to gain an idea of their expectations of new patients.

The process for new patients at Green Pastures Hospital (GP)

The person with a problem which he suspects may be leprosy, or for which he has been advised to go to GP, usually walks from the local bazaar the one kilometre through a rural village to the hospital. He (one in two or three patients reporting are women) approaches the hospital, a complex of one and two-storey buildings set back in fields. He walks up the path to the verandah which serves as the hospital entrance, Out-Patients Department (OPD), waiting and registration area. He takes his turn among others, tells the Registration Clerk where he has come from and what his problem is (in terms of physical signs and symptoms). He may be asked more about the nature of the problem. If the clerk is satisfied, his name, address, age, gender and so on are written on a card. He then waits to be called inside. He sits or squats on the verandah among others who are also waiting. Those waiting are usually leprosy patients. They can be "early cases" but are often "late cases"

with all stages of the disability and deformity. *Registration and wait may take 15 to 20 minutes.*

When his name is called, he is shown into a room with a high couch, desk and two chairs where a Nepali health worker dressed in white is sitting. He is asked to sit down and the health worker begins to question him about the reason for his coming, his problem, its duration, progress, measures he may already have taken to treat it and so on. He is then examined by the health worker who looks at and feels the problem area, his face, ears, hands and feet. He is then given a slip of paper and told to come back to see the health worker after having a "blood test", and his hands and feet tested. *This interview and examination may take 15 minutes.*

He goes out to the verandah again, walks down the path and across a field to the Laboratory (Lab.), a small building about 75 meters away. The sign outside says "No Admission Without Permission". Inside are two or three health workers sitting at benches, handling glass tubes and plates or looking into instruments. Here he is asked to sit on a stool. A worker takes some wet cotton, wipes his ear lobe, elbow and knee, and any skin patch. Then the skin in each place is pinched, and a small cut made. The side of the knife blade is scraped across each cut in turn. The blade is wiped on a glass plate and waved across a small flame between each cut. A small stick with cotton on the end is pushed up his nose and also rubbed on a glass plate. Each glass plate is waved over a small flame. A rubber tube is then tied round his upper arm and a needle poked into his arm and blood drawn into a glass tube and squirted into a bottle. *This procedure takes about 15 minutes.*

He now walks to the hospital buildings behind the OPD, enters through a doorway, past leprosy patients in beds and wheel chairs, crosses two courtyards to the Physiotherapy Department (Physio.), a room in the far corner of a second building. Here he waits for his turn then sits down on a stool in front of another health worker who sits on a chair beside a table. This time the health worker holds his hand or foot. He moves his

hands and feet, fingers and toes, wrists and ankles according to the health worker's instructions. He is told to close his eyes and point with one finger to the spots touched by the health worker. The health worker writes on a sheet of paper between each action. He may be given instructions on exercises he should do at home. He is given the paper which has been written on and told to take it back to the OPD. *This part takes between 15 and 45 minutes depending on how detailed the examination and instructions are.*

The person then returns to the OPD verandah, hands the paper to the Registration Clerk and waits to be called to see the health worker again. This time he is interviewed. He answers a long series of questions about the problem, has his body examined, skin looked at all over, his hands, feet, knees, elbows and face touched and felt by the worker. In this setting, if the personalistic beliefs of the patient emerge, they may either be disregarded or even belittled. The health worker writes on papers in a file and then hands him a small slip of paper. He may be told it is leprosy, or he may just be told he will be all right and to take medicine and come back in one or two months' time for more. He may also receive instructions about protecting his hands and feet with cloth and shoes, depending on whether they are numb or not. *This part of the process can take up to one hour.*

Finally the person takes his slip of paper and goes down the walkway into the hospital, to the window of a room in the first courtyard, the Nursing Dept. Here he hands the slip to (usually) a female health worker, is given some tablets to swallow on the spot and packets of tablets to take home with instructions on taking them each day. *This final stage of the process can take from five to fifteen minutes.*

Total time involved in a visit to GP

After adding time for the person to find his way between each department to the time taken in the process it seems that the person may spend over three hours on his first visit to GP. The OPD opens at 10 a.m., does not begin seeing any new patients

after 2 p.m. and closes at 4 p.m. For people who have to travel more than three or four hours to get to the hospital a visit involves two overnight stays somewhere in the town and one day at the hospital on top of the travel time.

What about the procedures and the instruments?

For people who have never been to a western medical centre before there are many aspects of this process and the procedures which would be foreign. Having another person handle one's feet, for example, is not just foreign, it is against cultural practices in Nepal. The author had personal experience of this in 1969. As a nurse in a remote village clinic one day I attempted to examine an old lady's ankles for swelling. She would not let me touch her feet and kept repeating the name of her god. I was informed that had she allowed me to touch her she would have committed sin for which she would have had to be purified.

Instruments such as scalpels and needles are also not common. The meaning of these to the patients was not explored at the time but from past experience I know that some of the instruments of western medicine are regarded as therapeutic in themselves. For example in the mission general hospital in Pokhara one day in the 1970s a Scottish physician was observed placing his stethoscope on the foot of a patient. When the amused observer asked about it, he said that the patient wanted the "digree" (from "degree", measuring temperature in degrees with a thermometer; Saral Nepali Shabda Kosh 2045:272) put there to make it better. Similarly I have heard it reported from many conversations of Nepali people that many regard an Xray as part of the treatment, not just as a western medical person would understand it, as part of investigations. As well as that, in general clinics Nepali people often request that their medicines be given by injection in preference to tablets.

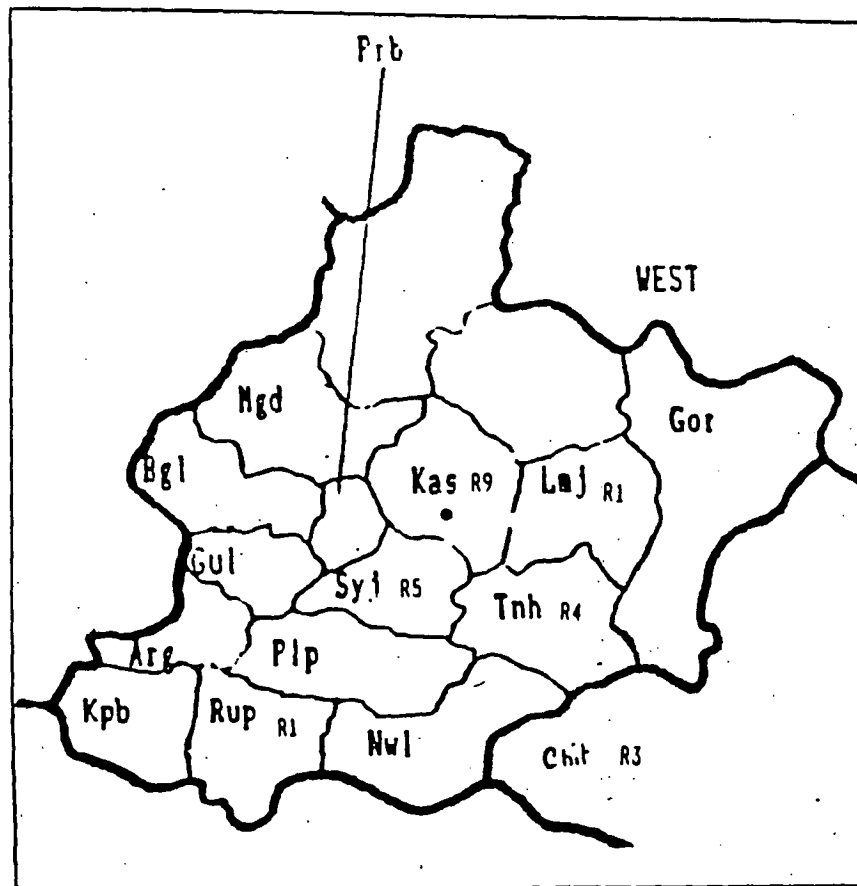
What happened to an actual patient?

On several occasions the researcher and assistant unobtrusively followed a new patient through their first visit. One of these was a well dressed-woman in her late thirties accompanied by her husband. She looked extremely distressed. In the OPD she was told she had come in good time and would be all right. In the Lab. conversation was limited to instructions about the smear and blood-taking. In the Physio. Dept., as her muscle weakness was found to be advanced, she was scolded by the Physio. technician for leaving it so long before coming. None of the five health workers who related to her talked *with* her, or asked her if she had any questions. The communication was mainly in the form of instructions and directed *at* her.

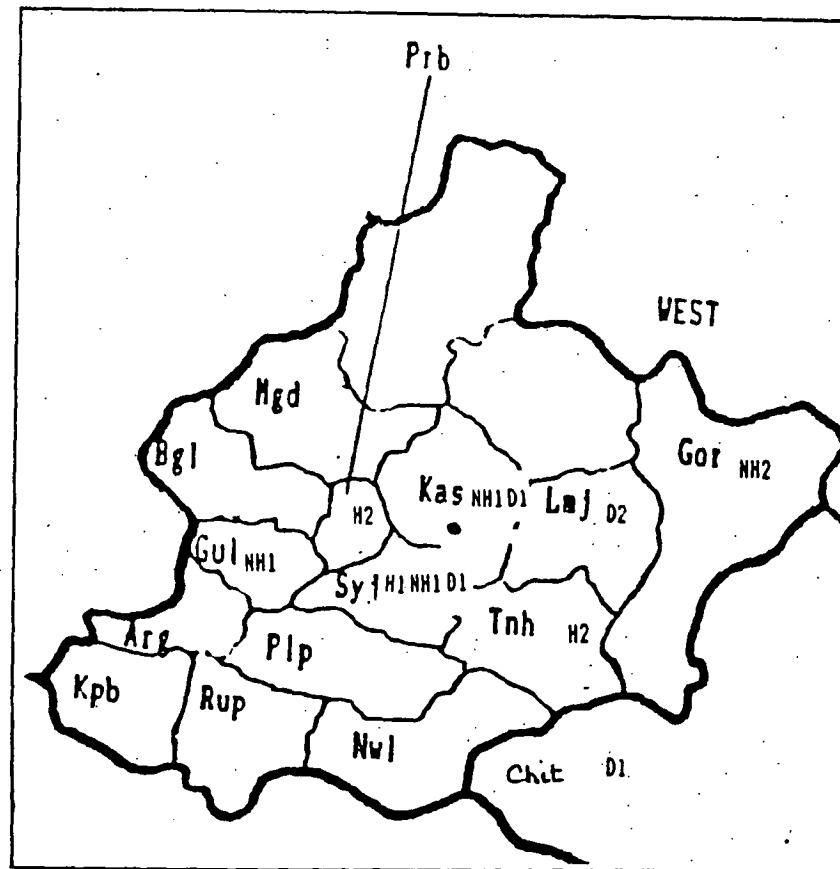
This lady was not one of the patients interviewed for this study: she did not know who the researchers were or what they were doing. Her emotional responses to what happened to her can only be guessed at. There is no need to guess, however, as a number of the patients interviewed did tell about their responses. During one interview a man expressed his feelings very strongly. (His case study is found in the Appendix).

Concluding remarks

In this chapter two worlds met. The distinct and overlapping ideas about leprosy found in the three Nepali words MAHAROG, KOR and KUSTHAROG were discussed and the explanations of health workers, the clinic routines and the encounter between patients and this care system were described. The responses of patients learning that they had leprosy, the relationship between responses, silence and withdrawal from clinic attendance, and differences in definition of leprosy and notions of cure are taken up again in Chapters 11 and 12.



a) Regular clinic
attenders: "R" & n.



b) Defaulters who were visited at home: "H" & n. Defaulters whose homes were visited but were not home: "NH"

c) Returnee Defaulter patients: "D" & n.

MAP B.

Western Development
Region of Nepal:

Distribution of
Patients Interviewed
in the study.

CHAPTER 11: PATIENT ILLNESS CAREERS AND COMPLIANCE

In the previous chapters the scene has been set for a focus on patient compliance. The scene includes the general medical system of Nepal and its particular application to leprosy. This complex and integrated medical system encompassing metaphysical, naturalistic and scientific facets of cause and cure is common to the communities from which the leprosy patients, and the Nepali health workers come. The people who seek help for their problem bear with them awareness of the likelihood of sanctions awaiting the revelation of a diagnosis of leprosy to their communities. They meet Nepali health workers who, through training and experience have changed their views, and are now more likely to adhere to a narrow scientific view of leprosy. The expatriate health workers espouse this scientific view as well, although some make additions. Certainly the leprosy services used by the patients are structured according to a scientific definition of leprosy, with the addition, at Green Pastures hospital, of the socio-economic dimension.

In this chapter the meeting of medical systems is further examined. This aspect of the research relates the qualitative meanings held by the patients to the earlier quantitative evidence from communities. A close examination of interview data lies behind descriptions of patient experiences. What is the psychological and social, as well as physical impact of having leprosy diagnosed? What influences decisions to comply (make repeated return visits to the clinic) or to discontinue their treatment? Are these decisions influenced by their beliefs about leprosy, or their emotional reaction to having leprosy or the threat of social consequences related to patient compliance? The research evidence answers all these questions. This chapter explores in particular the relationships to patient compliance of significant socio-cultural mechanisms and sanctions which underlie complex beliefs of illness and cure.

Framework for building patient illness careers

Patient illness careers provide a summary device for bringing together notions of several processes: the progress from

wellness to illness and return to wellness or healing; physical problems which stimulated seeking scientific medical help; record of attendance at the clinic; use of the concealment cycle; and outcomes in terms of physical, psychological and social dimensions of life.

As mentioned in Chapters 5 and 7, the interview guide used with patients covered topics designed to elicit patient illness careers including their explanations of leprosy. By conducting the interviews using a reflective style, interviewees were enabled to express their ideas and experiences using their own concepts. Analysis of the interviews using a modified grounded theory approach allowed the discovery of themes, sayings, and elements of patient experience or understanding of leprosy which could not be anticipated and would not have been found using a structured questionnaire or formal interview. The result of examination of the data in this way is the emergence of a more culturally informed understanding of leprosy and of patient decisions about clinic attendance in Nepal.

1. Origin or etiology of leprosy

Patient explanations of the origin of leprosy were presented in Chapter 7 and are shown to reflect the general community ideas and expectations. The relationship of beliefs about the origin of leprosy to actual clinic attendance is discussed below.

2. Help seeking

After the home and village advice is exhausted, there is resort to various kinds of practitioners. As Blustein found (Chapter 7) the various systems do not operate in isolation from one another so there may be several patterns of help seeking-behaviour such as simultaneous resort to a variety of practitioners, a hierarchic or mixed resort pattern beginning with one and adding others progressively, or exclusive, but changing, resort to a succession of practitioners. After obtaining advice or a prescription these may not be followed. The help seeking and remedies offered were summarised in Chapter 8, TABLE 8 :38 and in this chapter, TABLE 11:1.

3. Consequences of leprosy diagnosis and of sustaining treatment

One matter often spoken of in relation to compliance is the cost of attending. Cost may be estimated in relation to time, effort and distance as well as in terms of economics such as expenses and lost income. These matters were mentioned in Chapter 10. However there are other intangible costs or socio-cultural consequences which may also be of strong influence in this context.

This chapter presents the psychological burden, threats to social status, perceptions of religio-cultural consequences and role changes springing out of community beliefs and expectations; all associated with stigmatisation. This is one impact of the diagnosis of leprosy which all the interviewees faced. The patient response to the diagnosis of leprosy of employing a cycle of concealment to prevent others knowing and the relationship of this to compliance are presented and discussed as illuminated from interviews and development of the comparative "grid".

Do patient explanations of the origin of leprosy relate to their compliance decisions?

Patient groupings are organised according to their record of compliance in the following categories:

- 1) Newly-diagnosed patients (non-cohort) (12 patients)
- 2) Regular cohort patients (12 patients)
- 3) Defaulting cohort patients (10 pts followed-up - 5 interviews)
- 4) Defaulting but returned (non-cohort) patients (5 patients)

Are there differences in notions of causation between people from these compliance categories? If so, what are they? If not, are there other factors or differences which may relate to their decisions to continue, discontinue or resume their visits to the clinic for treatment? A close examination of the interview data shows the following:

In the new patient category six people mentioned metaphysical notions about fate and general misfortune (DASHA, KARMA, PAAP) as well as remarks like 'It is in god's hands'. Naturalistic notions of leprosy having to do with blood and heredity were mentioned by

three. Four mentioned notions connected with biomedicine such as germs and the idea of it spreading or being infectious. One person was sure what she had was ringworm (DAAD).

In the regular cohort patient category three people mentioned metaphysical notions to do with general misfortune (DASHA and PAAP). Blood, bone and the body (naturalistic) were mentioned by five and heredity was mentioned once. Two spoke of infection and germs (biomedical), one to say "They say it spreads - but...". Three notions are not mentioned in the new patient category but occur once each. These are witches and bad spells (JAASU), stinging nettles or ant bite and being "Touched by having no hands and feet".

Taking the "defaulter" patient categories together (those who stayed away and those who returned after a long absence) the metaphysical notion of PAAP was mentioned once, gods, witches, bad spells and spirits (KULDEVOTA - household god, BAAYU - spirit of the dead) three times and the general remark, "It is in god's hands", also occurred once. Naturalistic ideas of blood and heredity were mentioned three times and infection once. Two notions appeared which are not seen in the other categories. These are eating fish and "It is a bad disease, white leprosy called black leprosy when I was taking treatment". As well as that, the phrase "having no hands and feet" came up four times.

(See p. 206 for "white leprosy". "Black" leprosy is the expression of one patient and refers to the side effect of one of the anti-leprosy drugs which is a dye and is deposited in the skin resulting in a darkening. In people with pigmented skin the effect is that they look black. In fair skins it gives a red appearance. Being black presents a difficulty for many people in Nepal.)

Discussion

Each of these categories of patients shows a similar mix of notions of the origin of their problem. As is represented in TABLE 8:37 p. 177, the metaphysical, naturalistic and scientific are merged. Except for the idea of germs and infection and perhaps blood, these notions are not very close to the biomedical

explanation of leprosy. Even where the ideas of germs and infection are added into patient views, it seems not to have affected the compliance choices of these people. There seems to be little difference in pattern of belief about the etiology of leprosy between these three categories of patients. It could be suggested that neither a belief in a metaphysical origin of leprosy nor a more scientific belief seems to relate very closely to compliance behaviour in this sample of leprosy patients in Nepal.

On the face of it there may appear to be a significant reduction among defaulting patients of the mention of scientific notions related to leprosy. Scientific notions were mentioned four times by new patients, twice by regular patients and only once by defaulting patients. These results could be said to suggest some relationship between holding scientific notions and continuing on treatment. There are two difficulties with such an assumption however. First, a comparison between the new patients and defaulting patients is not helpful; in fact it may be misleading, as the new patient category includes people who will later in their career probably become defaulters and others who will continue their treatment regularly. It is too early in their career to be sure. Secondly, the numbers are so small that further study would be needed to determine whether this is a real association or not.

THE CONSEQUENT IMPACT OF A DIAGNOSIS OF LEPROSY

What impact did the diagnosis of leprosy have on these people? A selection of responses to the diagnosis is presented in Table 11:1. These responses illustrate the psycho-social impact of leprosy on these people, the severity of which led to the following small study of the emotional burden of leprosy.

TABLE 11:1

PATIENT HELP SEEKING AND THE PSYCHO-SOCIAL IMPACT OF THE DIAGNOSIS OF LEPROSY
Examples from a Selection of Patients

| Initial Sign/Problem | Action before Diagnosis | How diagnosed | Impact of diagnosis |
|---|--|--|---|
| <i>Interview 1. (See Illness Career FIVE in this Chapter.)</i> | | | |
| A blister in knee but the place had no sensation so it was not a problem. | | One day he was at home listening to the radio and heard a leprosy spot which said if one had certain signs to go to the health post for examination. Next day he went to Pokhra to the doctor who sent him to Green Pastures Hosp. | Mind is "down". No trouble in his village. He left his job with the Police. (His notes show that he was dismissed.) |
| Burned himself with boiling water, large blister resulted but that place was also anaesthetic. | -->went to LAMAJHAKRI 2/4 days. Made a vow (BHAKAL) | | |
| <i>Interview 7 (See Illness Career FOUR in this Chapter.)</i> | | | |
| Patches on knee. | -->did nothing 2/3 yrs | As swelling and patches got worse, she could not walk, she and husband came to Pokhra and then to Green Pastures Hosp. | Her husband abandoned her. After hearing the diagnosis all her strength left her. |
| Then swelling and red patches came over hands feet and many parts of the body. | -->then went to see JHAKRI | | |
| <i>Interview 8</i> | | | |
| Painful feet 'eaten by mud'. After some days noticed patches on his body. While in the local health post with his child noticed poster with description of signs and symptoms of leprosy which matched his own. | --> Blew PHUKNU | Started to take DDS from the Health post. Got an ulcer between his toes and the HP worker referred him to Green Pastures. GP sent him back to the HP to get a letter before he was helped. | Fright. Mind went UDIHALYO 'If I have to cut off my hands and feet who will look after my children?' He wept during the interview and told of a dream he had just before coming to GP of people with hands and feet and heads bandaged. |
| <i>Interview 13</i> | | | |
| Felt sharp pain beside the ear for 5/6 years. Pins and needles for more than 10 years. | Called the LAMA JHAKRI who said it was because of angry god. He offered PUJA, sacrificed goats, chickens for that and made sure the family god was not offended for some reason. | Eventually he went to Western Regional Hospital and was referred to Green Pastures. | He is very worried but says he can't die. He has some doubts that the medicine can make better. He says if he could get better soon that would be a wonderful surprise. |
| Then patches started to come on his back, arms and thighs. The pain got worse, he could not climb trees and he felt a lot of pain when stepping on small stones also. | He did not call the LAMA JHAKRI for his patches because his father had spent his life going to them for his patches (and they | | |

| Initial Sign/Problem | Action before Diagnosis | How diagnosed | Impact of diagnosis |
|----------------------|--|---------------|---------------------|
| | were the same as his). He vows strongly that he will never call a LAMA Jhakri ever again. He went to a medical practitioner once but he could not recognise his problem. | | |

Interview 15 (See Illness Career ONE in this Chapter.)

| | | | |
|---|---|---|--|
| A small white patch on the arm for 7/8 months | He came to know about leprosy from school books. He tried the juice of bean leaves before going to the health post. | The health post staff advised him to go to the mobile clinic at Walling but he decided to come to Green Pastures for a thorough check-up. | He still has doubts as to whether he has got leprosy. He is not going to tell his friends in the village anything. |
|---|---|---|--|

Interview 19

| | | | |
|---|--|---|---|
| For 5/6 months he has had patches on the body and legs. They were small but now are getting bigger. | He went to Bharatpur Hospital for treatment, got some ointment and tablets there but they did not help him. He used juice of bean leaves thinking they were ordinary ringworm patches. He also thought it could be from the angry god or goddess. He fulfilled a vow (BHAKAL) to the god with no result. | He says his reason for being in Pokhra is to look for a job, not because of his illness. Some of his friends told him that at Green Pastures an American doctor will see him well and cure him, so he came to Green Pastures. | He says he does not know what his problem is and is afraid and worried about how it can be cured. |
|---|--|---|---|

"Having no hands and feet"

This expression was encountered repeatedly in the patient interviews. It gives a glimpse of the meaning of leprosy, Kushtharog, to some of the people in the study. Kushtharog was also referred to in this way by the wife of one of the "defaulting" patients interviewed. These people seem to be saying that to have Kushtharog is to be doomed to having no hands and feet.

PSYCHO-SOCIAL CONSEQUENCE OF LEPROSY

Depression seems to be a significant consequence of leprosy in Nepal. An expatriate nurse at GP remarked: *"There is a depressive element to the place... A patient committed suicide here last year... The depressive side of the illness is not*

taken into consideration." A number of the patients interviewed in this study exhibited very strong responses when asked about how things were for them. For example, as seen in TABLE 11:1 above, when asked how they felt when they first learned that they had leprosy some spoke of their minds being in turmoil, not wanting to eat or talk to anyone, not sleeping, despair, anger, fear of rejection and so on. Several interviewees, both men and women, wept openly during our conversations. These seemed to suggest clinical depression as defined by western biomedicine.

The researcher was prompted to discuss the matter with mental health experts in Kathmandu. The result was a small study of interview patients using a WHO standard Self-Reporting Questionnaire for assessing possible "neurotic caseness". The findings of this small study of the emotional burden of leprosy are presented and discussed now. Two case studies which illustrate the impact of leprosy on lives are found in the Appendix.

The questionnaire was not a diagnostic instrument, rather, if positive results were found, they were regarded as indications that the patients may be clinically depressed and need to be professionally assessed. Although this study was small and incomplete, it did point up an aspect of leprosy at present largely overlooked in care programmes. From the results of this study, it seems that people coping with the knowledge of having leprosy and trying to keep it secret are more likely than the general public reporting to general health facilities to be suffering from depression.

[NOTE: Some clinicians and academics, among them Kormann (1990), Nichter (1981), Ullrich (1987), Fabrega (1977), Bebbington (1978), Marsella (1978, 1980), Weiss (1985,1990), and Ying (1990), express disquiet about the appropriateness of cross-cultural diagnosis of mental health entities using diagnostic criteria emanating from western cultures. Cross-cultural psychology is a large subject, discussion of which is beyond the scope of this report. However the diagnosis of depression in

the context of the complexity of the medical system of Nepal is important in an ethnomedical approach to leprosy in Nepal.]

Mental health in leprosy in Bombay

Mitchell Weiss, of Harvard Medical School, in a paper presented at the Third International Conference on Traditional Asian Medicine in January 1990, reports on an ongoing study of leprosy patients in Bombay, India. He discusses the **emotional burden of leprosy** and suggests that "some patients found it difficult to reveal the full extent of the impact of their illness and how deeply troubling...the thought of this diagnosis (is)". Weiss's reported study included 56 leprosy patients, 19 with vitiligo and 12 with tinea vesicola. For evaluating depression, anxiety and other emotional problems systematically, he used the Combined Hamilton Depression and Anxiety Rating Scale among other tools. (He did not use the SRQ.) He reports that "both depression and anxiety were severe among some of our subjects with leprosy..., but **depression was more frequently a serious problem**". His work is centred on leprosy in Maharashtra, South India. Responses to leprosy and its meanings by sufferers in Maharashtra and Nepal may show many similarities as the Marathi and Nepali languages enjoy a common root (Sanskrit), a common script (Devanagiri), and a similar Hindu cultural heritage.

Specifying psychiatric disorder in leprosy: A dilemma

Weiss states that there is a failure in leprosy care to specify psychiatric disorders, "perhaps in an effort to spare someone the additional burden of a further stigmatising diagnosis". He suggests that this "... failure to specify a psychiatric disorder ... obscures epidemiological information about the range of emotional responses ..."; as well as that "... it may fail to mobilise clinical attention that could benefit a patient." Like Wright, who suggests that the SRQ may identify "... patients in need of further assessment of their mental status", Weiss goes on to suggest that "patients can benefit significantly from clinical attention to this aspect of leprosy".

Mental health in Nepal: A basis for comparison

The Wright et al. (1988) study, carried out by Community Mental Health workers near Kathmandu, provided a basis for comparison of leprosy patient responses. A Self-Reporting Questionnaire (SRQ) developed by the World Health Organisation (WHO) was used. It had previously been used in a collaborative study by Harding et al. (1980) in Sudan, Colombia, the Philippines and India. The SRQ consists of 20 questions designed to detect neurotic disorders. Translation and back translation had established a standardized Nepali version which was used in this study by Wright et al. (1988). Their study examined two populations, 148 out-patients at a rural primary care facility, and 101 at a district hospital out-patients department.

Meaning of "caseness": Cut-off point for "psychiatric caseness" (neurotic)

Various studies in different countries have set "case" cut-off points at differing levels. Wright et al. established the cut-off point for 'psychiatric caseness' for their study at 10/11 positive responses for the 20 questions. The 10/11 cut-off point "has a specificity of 91%, and a sensitivity of 74%". Wright et al. suggest that "positive findings might not necessarily represent hard psychiatric morbidity, but rather *patients in need of further assessment of their mental status*". They also suggest that "positive findings might also reflect these symptoms used as *a means of expressing hardship*".

Patients included in the study

The total number of patients who answered the questionnaire was 21, of whom 16 were attending Green Pastures Clinic and five were the "defaulter" cohort patients interviewed at home. The 16 Green Pastures patients included six newly diagnosed, nine regular cohort patients and one returned "defaulter" patient. The aim to use the SRQ with *all* interview patients was only partially fulfilled. Of the total 34 interview patients, 21 (61.76%) answered the SRQ.

The aim of using this SRQ in the interview study of leprosy patients was to look more deeply into the emotional responses to the burden of leprosy. The questions are found in TABLE 11:2 below.

TABLE 11:2

20 Question Self-Reporting Questionnaire:

1. Do you often have headaches?
2. Is your appetite poor?
3. Do you sleep badly?
4. Are you easily frightened?
5. Do your hands shake?
6. Do you feel nervous, tense or worried?
7. Is your digestion poor?
8. Do you have trouble thinking clearly?
9. Do you feel unhappy?
10. Do you cry more than usual?
11. Do you find it difficult to enjoy your daily activities?
12. Do you find it difficult to make decisions?
13. Is your daily work suffering?
14. Are you unable to play a useful part in life?
15. Have you lost interest in things?
16. Do you feel that you are a worthless person?
17. Has the thought of ending your life been on your mind?
18. Do you feel tired all the time?
19. Do you have uncomfortable feelings in your stomach?
20. Are you easily tired?

Results from use of Self-Reporting Questionnaire in Nepal

In this leprosy patient population the overall finding was neurotic "psychiatric caseness" of 52.38% (11 out of 21), that is 10 out of 16 (62.5%) clinic attenders and one of the five (20%) "defaulter" patients visited at home. This is almost twice the level found among the urban outpatients by Wright et al: They found 9% 'caseness' in the general population, 19% in a rural population reporting to rural primary health care and 27% among those reporting to an urban district hospital out-patients department. (See p. 255 for further discussion of these findings.)

TABLE 11:3

Results from use of Self Reporting Questionnaire in Nepal

| Levels of "Psychiatric Caseness": | | | Average SRQ sum-score |
|-----------------------------------|-----|---------|---|
| Normal Population: | 9% | (n=101) | 4.2 |
| Rural Primary care OPD: | 19% | (n=148) | 6.4 |
| District Hosp OPD: | 27% | (n=150) | 7.3 |
| Psychiatric OPD: | 74% | (n=100) | 27.3 |
| | | | <i>Wright et al. (1989) Nepal Findings</i> |
| Leprosy Interviewees | 52% | (n=21) | 9.1 |
| | | | <i>Hyland (1990) Nepal Leprosy Findings</i> |

Weiss mentions the dilemma faced by clinicians when considering the appropriateness of 'diagnosing any disorder ... in response to an extreme stressor like leprosy, for which it might seem a

marked emotional response is reasonable and its absence abnormal' (1990). It was not a surprise to find positive indications of neurosis among these leprosy patients in Nepal as these had already been noticed. Perhaps the responses point to how these people see life.

The typical patient positive for "psychiatric caseness" according to the frequency of affirmative responses ... *feels nervous, or tense, easily frightened, unable to play a useful part in life, has frequent headaches, sleeps badly, finds it difficult to make decisions and think clearly, is easily tired, feels unhappy and has thoughts of ending life.*

The typical picture of the non-"caseness" is the same except that they *sleep better, make decisions more easily and are not easily tired*, but they still *feel their daily work suffers and they have lost interest in things*. For the patients involved in our study the responses seem to reflect something of how they experience life as a leprosy patient in Nepal. There seems to be a cruel irony in asking ill, deformed, socially dislocated and stigmatised leprosy patients some of the SRQ questions.

Is this phenomenon a reaction to the diagnosis or is it associated with other factors as well? Is it true for those who have no deformity or disability? Is it true for those whose home and family life continues as it did before they contracted the condition? Does it only apply to those who are disabled and socially separated?

Immediacy of diagnosis

Weiss suggests that "a marked emotional reaction" could be seen as normal in the circumstances of leprosy. Even though they had been on treatment for leprosy for upwards of three years and had no physical deformity, six of the "old" cohort patients were positive neurotic "cases". As this depression was still present after three years it is possibly not reactive depression. What is the relationship between "psychiatric caseness" and physical disability?

Disability

Information on disability was available for 20 of the 21 patients with whom the SRQ was administered. Thirteen patients questioned had disability (WHO grades 1, 2 & 3) and seven did not. Of the thirteen disabled patients nine were "cases" according to the SRQ and four were not. Of the seven patients with no disability, two were "cases" and five were not.

TABLE 11:4

Psychiatric "Caseness" Related to Grade of Disability

| Disability Grade * | Patients +ve for 'Caseness' | Patients -ve for 'Caseness' | Total Number |
|--------------------|-----------------------------|-----------------------------|------------------------|
| 0 | 2 | 5 | 7 |
| 1 | 0 | 0 | 0 |
| 2 | 8 | 5 | 13 |
| 3 | 0 | 0 | 0 |
| Total | 10 n=11 (1 missing) | 10 | 20 n=21 (1 missing) |

TABLE 11:5

Psychiatric "Caseness" related to the Extent of Disability

| Disability Extent ** | Patients +ve for 'Caseness' | Patients -ve for 'Caseness' | Total Numbers |
|----------------------|-----------------------------|-----------------------------|------------------------|
| 0 | 2 | 5 | 7 |
| 1 | 1 | 0 | 1 |
| 2 | 2 | 1 | 3 |
| 3 | 1 | 3 | 4 |
| 4 | 1 | 0 | 1 |
| 5 | 1 | 0 | 1 |
| 6 | 2 | 1 | 3 |
| | 10 n=11 (1 missing) | 10 | 20 n=21 (1 missing) |

* Disability Grade, WHO. (see page 117)

** Disability Extent. Number of sites involved

Ranges from none or 0 to both hands, both feet and both eyes, in other words = 6 sites. (Devised by Author to give some indication of the extent of disability the patient experiences.)

TABLE 11:6

| Obvious Disability | Neurotic "Caseness" | | |
|--------------------|---------------------|----------|----|
| | Positive | Negative | |
| yes | 9 | 4 | 13 |
| no | 2 | 5 | 7 |
| Total | 11 | 9 | 21 |

Analysis of table 11:6 shows an odds ratio of 0.18 with Fisher exact 2-tailed probability of 0.2033176. From this sample there seems to be no significant relationship between disability and neurotic "caseness".

However, as the numbers in this study are small and incomplete, it is not possible to state there is no actual correlation between visible disability and depression. The findings are suggestive enough that further study could usefully look into the relationship of disability (both grade and extent) and possible "psychiatric caseness".

It may be that the writers in Hastings (1985) chapter on Rehabilitation (1985:287-319) are correct when they state that "we are convinced that the horror and dread of the disease are rooted in its deformity". Certainly the term having no hands and feet represents a dread held by patients and family members. Deformity may be one factor associated with the emotional burden of leprosy, but its relationship is not clear.

It may also be of interest in the Nepal context to look into why the two "cases" with no physical disability are women. In the cultural milieu of Nepal women do not enjoy the same individual and independent geographic mobility as men. Women represent only about one third to one half of registered leprosy patients. It would be of interest and of possible use to health care administrators to explore comparisons between men and women in relation to the impact of diagnosis and the emotional burden of leprosy, and the extent to which their lives are disrupted because of it.

Family life disrupted: Separation

The findings on psychiatric "caseness" were laid alongside information on the living circumstances of the patients. Some of the interviewed patients had separated themselves, been isolated or expelled since their leprosy had become generally known. It was found that of eleven patients who were living separately from their families seven were "cases" and four were not. Of twelve disabled eight were "cases" and four were not. Of six patients who were both separated and disabled five were "cases" and one was not. Of four patients who were neither separated nor disabled one was a "case" and three were not. The phenomenon of separation was discussed in Chapter 9. Perceived threat of

separation appears to be associated with patient decisions to discontinue treatment.

PATIENTS WHO STAYED AWAY

Since one of the basic aims of the study is to gain new insights into the reasons people with leprosy discontinue their medical treatment, it is vital to carefully examine the explanations and experiences of those who actually did that. As was detailed in Chapter 5 the research assistants made the difficult and time-consuming journeys to the mountain village homes of ten cohort defaulter patients. It was not possible to interview five of these. They were no longer at home with their families. The research assistants were able to obtain some details of their stories from relatives and neighbours. The remaining five people all agreed to a tape-recorded interview, a brief physical examination and to answer the self-reporting questionnaire. The research assistants wrote a comprehensive report on each visit. As well as this information all their hospital records were open to the researcher. It was possible to build up a picture of the situation of each person.

In the follow-up study of ten "defaulter" patients from Green Pastures Hospital the research assistant's report is enlightening. It is presented in full in the Appendix on illustrative case histories. Excerpts are included here:

1. It was possible to meet only six of the ten patients at their homes. They were Sri. Pariyar, Ali, Sunar, Sharma, Magar and Dama1.
2. It was found that among all the patients six having spent more than 15-20 years in India in a variety of occupations were not living at home. These were:
 - a) Sri Pant (Non-permanent work)
 - b) Sri Pariyar Army
 - c) Sri Magar (Non-permanent work).
 - d) Sri Sunar (Factory)
 - e) Sri Sharma (Non-permanent work)
 - f) Sri Magar (Factory).

3. It was understood that some patients had gone to India since the disease struck. These were:
 - a) Sri Magar. When he was small he was in India but having come back to Nepal he had not gone to India again. Now after about 45 years he had returned to India.
 - b) Sri Jaisi. He had never been to India, but when he got the disease he went to India both to get treatment and to work to earn his living. (See Illness Career SEVEN in this chapter.)
4. But Sri Pariyar was one patient who left his work in India early. He said that he thought treatment was easier in Nepal. Among the patients met he appeared to be the most anxious and he was the only one found to have "reaction". (Reaction: physical symptoms of immunological instability such as fever, crops of painful red lumps, joint pains, swelling and so on.) He was the only one of the ten who was found to be continuing to take medication from a second place.
5. Some patients after returning from India found that they could not get on with their families, and their families were not caring for them either. These were:
 - a) Sri Sharma
 - b) Sri Pant.

Neither of these patients' families was found to be stable (permanent). According to the explanation given after questioning it was understood that Sri M. Pant had "gone mad". It seemed that from before the disease was recognised in either patient there were family quarrels about property.
6. Sri Ali (See Illness Career SIX in this chapter), Sri Sharma and Sri Magar all seemed to think that they would probably get better now without taking medications.
7. Sri Damai was the only patient who was not only not ready to be interviewed but who ran away when we met him. It was found that after this patient got the disease and his family found out they had not given him advice to take medicine. It was found that one of the family members was angry when it was said that Sri Damai was a leprosy patient (*Kushtharogi*).
8. All the interviewed patients and their families had found the black discolouration of the skin resulting from the medication, and their neighbours continually asking about it to be a problem (difficulty).

9. None of the interviewed patients could say it was definitely leprosy (*Kushtharog*).
10. Only one patient, Sri Sunar, explained that the reason he could not come for medicine was economic and physical (bodily) weakness.
11. Two patients, Sri Pariyar and Sri Sharma, were found to have left their villages together with their wives and children and were living and working in another place.

The interview with one man who had stopped attending the clinic illustrates many of the points discussed in this chapter. This interview (I39) is reported in full in the Appendix and is summarised here.

To this patient his *problem* was a swollen knee patch with pain (reversal reaction). After 13 time-consuming and costly weekly journeys to Green Pastures, 13 weeks of steroid therapy and doing the prescribed (and costly) PUJA to the household god, this was *better and he felt relief*. Along with this his skin had become *black* from the medicine and his neighbours had *begun asking* about his colour, and his frequent trips away. He had told no-one about his condition and did not want them to know. He had seen patients at GP with *no hands and feet* and this made him afraid. His duty to his family and community kept him *at home for the maize planting* so he could not keep his appointment on time. He had overheard patients who were late for their treatment at GP receiving a *telling off* by the staff. He anticipated this same *threatening* if he went back late. **He did not go.** The story of this man is very similar to that of Illness Career SIX.

It is of interest that this interview illustrates the kind of deception or *concealment* that Miller (1990) describes from his work in a village in a neighbouring district. In the life of village Nepal there is little or no privacy; everyone knows and is curious about what others are doing, planning and so on. There are elements of family life, such as a member having leprosy, which must be kept quiet. Various techniques are used to keep others from knowing and perhaps using the information against the family by manipulating it to their disadvantage.

Here "concealment is self-defence" (Miller 1990:145). This technique is "... especially used when people decide on a course of action that flies in the face of society's norms" (1990:160). This concept helps us to understand what is happening when the patient does not want to admit matters on the record. It also applies in his keeping his condition quiet and his anxiety when he became black and was away from home so often. Concealment is achieved through *keeping silent* and through *deception*, that is "saying something and not saying what (it is) wished to keep secret". Words which are not literally true are thus used as a *shield*, to protect the family reputation, prestige and well-being (1990:145). Miller also refers to the use and misuse of words, and reluctance to have them recorded (on paper). Perhaps the fear of the tape recording can be explained too. In the largely non-literate society of village Nepal, Miller maintains that:

Face-to-face oral communication can be adjusted and fine-tuned to a situation in a way that written communication can never be. Words in black and white (or on tape) cannot be manipulated so easily (by the speaker) nor is there any way to foresee and take into account the moods and dispositions of those to whom the communication is addressed at the moment they receive it. (1990:144)

In his conversation with the interviewer before the tape was turned on the patient talked more freely, but one suspects warily as he was addressing an educated, literate high caste man and an outsider. The dominant social group in Nepal, the Brahmins and Chhetri, some of whom form the literate few in some villages, may be seen to have a remarkable eloquence with spoken words but also to have the ability "... to manipulate written documents, if they wish, to the disadvantage of the illiterate many". So in his oral communication the patient was able to use his skill and techniques of concealment, adjusting his words to suit the situation and audience. But when faced with the tape recorder, and the consequences, non-adjustable words potentially manipulable by others, he became very cautious. Miller states that "stories of this ... manipulation [of written documents to the disadvantage of the illiterate] are familiar to villagers who are thus understandably wary of the *written* [recorded] word" (1990:144).

The explanations reported in the previous chapter included those of the patients who had stopped coming to the clinic for their medicines. From these explanations there seemed to be no difference between those who kept coming and those who did not. This applied particularly to notions of cause of leprosy. Further analysis, however, did reveal some factors which shed some light on decisions to discontinue medical treatment.

PATIENT INTERVIEW DATA RE-VISITED

Further steps in the process of analysis of the interview material aimed to look beyond the models and themes already studied, the explanations and experiences, and to examine and ask other questions of the data. What are these data saying about these people and their decisions in relation to their treatment for leprosy?

First, the responses from each of the four categories were examined in turn as part of the construction of the comparative "grid" and the following questions were asked of the data:

1. Why did those who had been absent return again?
2. Why did those who continued to be absent stay away?
3. Why did those who persisted keep coming back again and again?

All the transcriptions and translations of interview were read again and notes made of recurring expressions and events which seemed significant. Lists were made in relation to the account given by each person. A short list of aspects related to decisions to stop, return, persist and so on were made. Out of this process some new aspects of the picture came to light.

1. Many respondents had made use of personal or ethnic networks of contacts, people who knew, for gaining entry to the treatment at Green Pastures. Hamro manche, Hamro gaunko manche (our person, or our village person) are two common expressions found in the transcripts.
2. Almost without exception the respondents had kept silent in an endeavour to conceal the diagnosis of their condition. In particular it was concealed from the wider village community, but in some cases from their extended and nuclear families as well.

3. It seemed that some events or conditions had acted like a 'trigger' to respondents' possible exposure to their community members as leprosy patients.

Secondly, two of these new aspects, namely silence and imminent exposure, were examined further as they could perhaps relate in some way to decisions about compliance. Common patterns were sought and in particular the question was asked: "Is it possible to identify any stage at which a person may be at risk of dropping out of treatment?"

Thirdly, in order to seek answers to this question, a grid was constructed (see Chapter 5). All the interview material was read over again. Factors listed on the grid were noted down for each respondent in each category. This exercise was done on large sheets of paper. Factors to be listed were placed down the left margin and a column added for each individual respondent. The factors listed on this grid were:

1. Individual patient factors are gender, caste, type of leprosy, smear result, disability grade, initial "acute" problem, active case or not, time travelled, number of times attended clinic, number of times late.
2. Help-seeking factors like use of own people.
3. Illness problem: Is it better, persisting, recurrent, or new and different?
4. Concealing: Who knows about their condition? Is there suspicion, slander or confrontation and labelling?
5. Possible 'triggers' to exposure listed.
6. Living situation: Are they still with their family or not?
7. Clinic factors: their reception/lost in the system.
8. Other factors.

Fourthly, after construction and study of this initial grid it was condensed and reconstructed with systematic re-examination of each category of respondent focused particularly on:

1. The process of "silence" to "exposure" in the community.
2. The process of "withdrawal" (separation) or "expulsion" from the family and village.
3. Possible "triggers" or crisis points in these processes.

4. The decision to stop, return or persist with treatment.

Finally, this new grid was then studied in detail to search for possible links between the first three and the last factor on the grid. This time the grid was placed on a double page of a notebook for convenience.

This step-by-step process of analysis and refining had clarified elements of the socio-cultural interplay which seemed to underly the decisions individual leprosy sufferers made in relation to their treatment. Some associations seem to emerge while other elements seem to have no relationship with decisions about treatment.

FROM SILENCE TO SEPARATION AND CONCEALMENT

At the end of this process it was possible to describe the progression from silence to separation. Different degrees of separation found among leprosy patients interviewed in Nepal in 1990 were as follows:

1. Remains in family (extended or nuclear as normal).
2. Remains in family but "privately isolated" ("not touched").
3. Has moved with nuclear family to another community.
4. Has moved alone to new community (legitimate).
5. Has been "expelled" alone (no community) (family may also be discriminated against here).

Degree of separation related to compliance category

Those remaining on treatment were found to be:

1. Remaining in family..... "silent" and "safe".
2. Withdrawn with family to new community... "silent" and "safe".
3. Separated within home....."private exposure and isolation".

NOTE: All had continuing physical problems.

Those patients who have resorted to withdrawal from treatment were found to be:

1. Remaining in family "silent but threatened".
2. Moved with family to new community... "silent but threatened".
3. Withdrawn alone "silent and threatened".

4. Expelled alone "public exposure and public expulsion".
NOTE: None had a pressing physical problem any longer.

Those who returned again for treatment after a long absence were found to be:

1. Separated in the family..... "private exposure and isolation".
2. Withdrawn alone..... "silent but threatened".
3. Expelled alone "public exposure and public expulsion".

NOTE: Each had a new and pressing physical problem.

Physical problem and compliance

As indicated above the continued presence or return of a perceived physical problem seems to be associated with the continuation or the re-commencement of treatment after an absence. The latter may be in line with the findings of Neylan et al. (1988) and is discussed on p. 264.

Silence and the concealment cycle

It seemed clear that the fact of having leprosy or being likely to become a *Kushtha-rogi* (a leprosy sufferer) was a matter about which it was important to keep quiet. Why? Because it was a matter which, if it became known to outsiders, could be, and was at times, used to the disadvantage of the person and his family. The matter of self and family PROTECTION THROUGH SILENCE seemed to be important to most of the respondents.

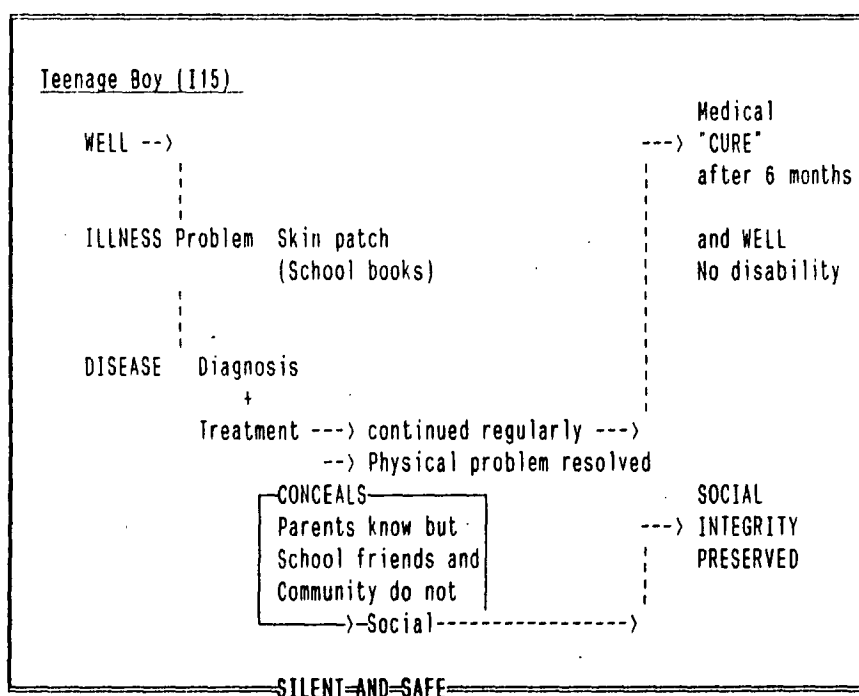
An association between threat of exposure and withdrawal from treatment was found. This is illustrated in the following patient illness career diagrams where some remain silent and others resume silence after withdrawing.

LEPROSY PATIENT ILLNESS CAREERS: NEPAL 1990

Nepali leprosy patient illness careers illustrate a spectrum of results, bringing together the concepts of wellness-illness-cure and social integration-separation-exposure, with the concealment cycle the central element of the process. The illness career is conceived of in terms of movement from wellness to illness and cure or restoration of wellness. In this model the physical, psychological and social integrity of the person is noted.

The illness career graphic represents the patients' lives in outline. Their progress from being well to recognition of a problem which they perceive as illness, then their diagnosis by an expert to have the disease of leprosy is shown. Then their record on treatment, their psychological response (caseness status) and the place of the concealment cycle in their careers are represented. Finally the outcome in terms of restoration of wellness, medical cure, physical deformity and social status are presented. "Well" represents their status before the problem was a stimulus to seek help. For some this status was restored, for others it was not. Medical cure represents a biomedical concept used when patients complete their anti-leprosy medicine. For some this cure contrasts with their physical condition which may or may not mean enduring or progressive disability and deformity. The social status of patients at the point of the study report may be undisturbed or disrupted.

ILLNESS CAREER ONE



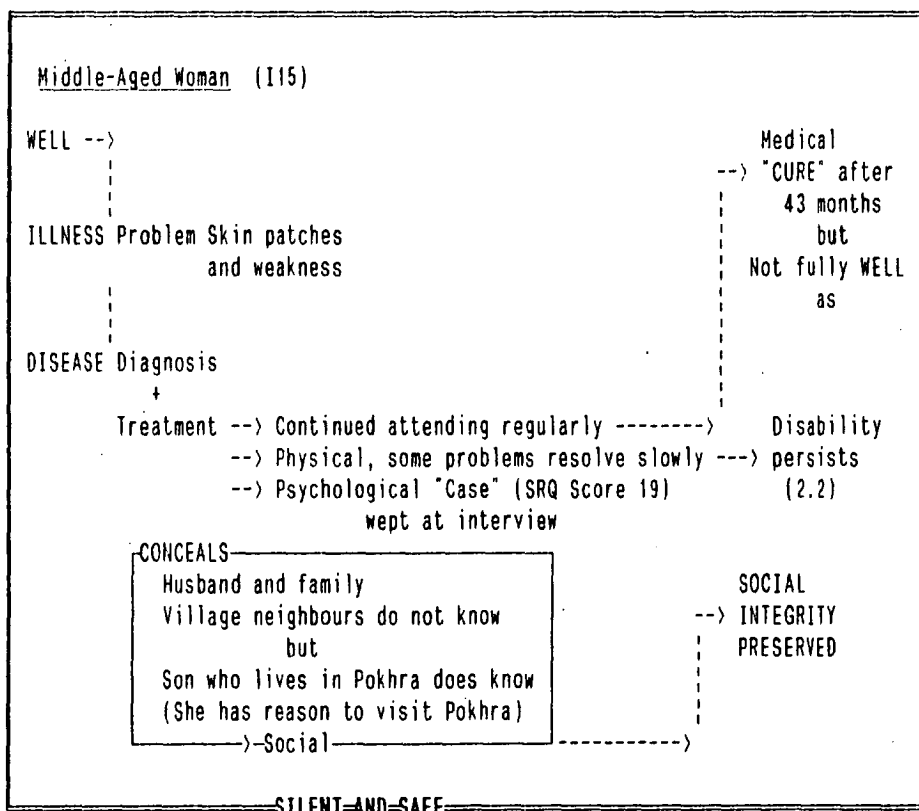
This boy learned of leprosy from his school books. The patch he had on his arm was like the descriptions he read. He knew that medicines were effective for leprosy. He was told his type of leprosy was not infectious and needed only six months' treatment.

He came regularly, completed his treatment, had no visible signs of leprosy whatsoever. However he was concealing his condition from his school friends and village neighbours.

ILLNESS CAREER TWO

People with leprosy are isolated individuals, not a group.

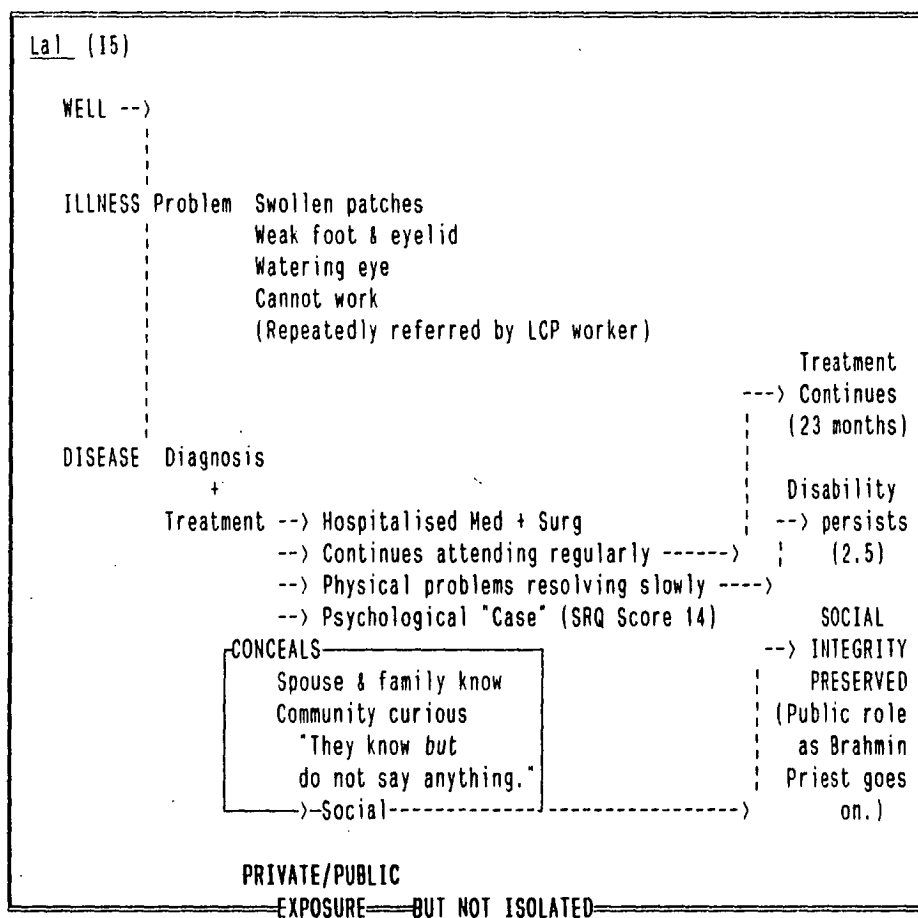
This illness career illustrates an observation I make about leprosy patients. They are not a group, in that they are not personally associated with each other, nor do they meet in some association with a common purpose. Rather they can be spoken of as a category of person. They remain very isolated and alone as people. They are individuals with a heavy secret, anxious that it not be discovered. This lady shied away from the hospital entrance one day when we were talking to her. A distant relative had arrived and she did not wish to be seen there.



This lady said leprosy was a curse from god. She was doubtful about the idea of a micro-organism. When asked why she took medicines then, she replied that perhaps she would get better. She bore her secret anxiously and alone for years before being able to speak of it with the interviewer. She wept with us.

Even though she has been medically "cured" and has preserved her place in her home and village community, her social integrity, she retains some permanent physical disability.

ILLNESS CAREER THREE

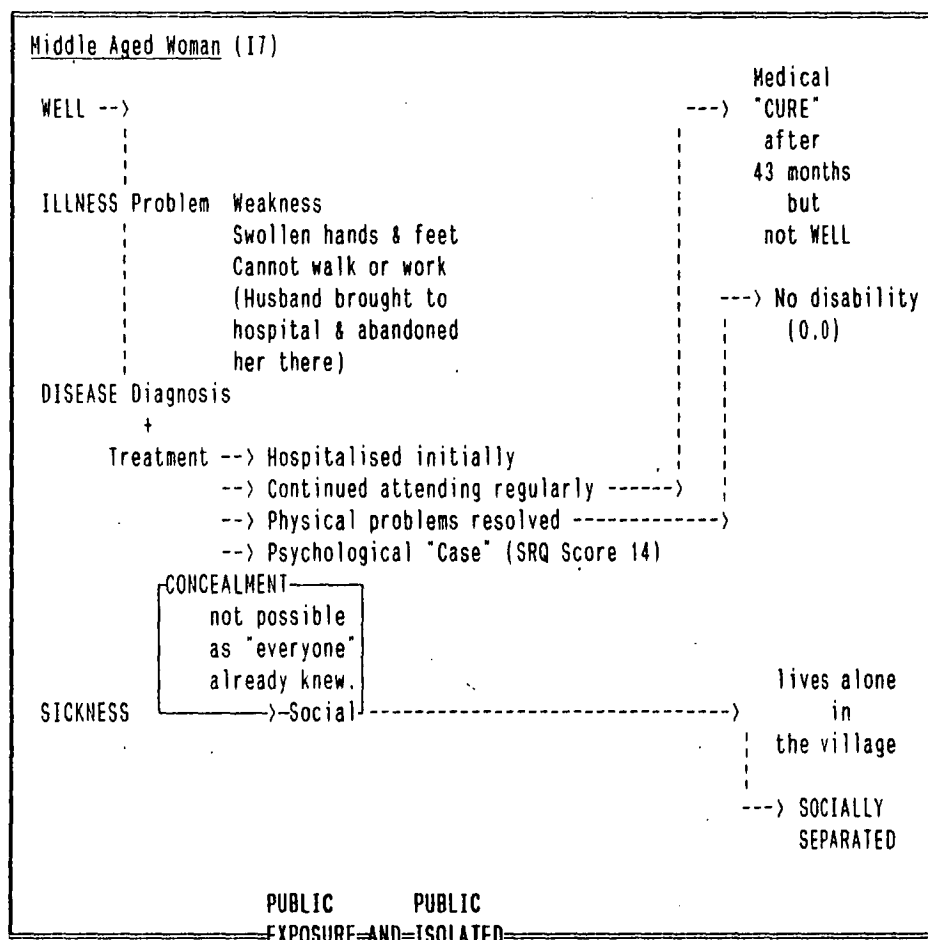


This man is the older of two members of the same family who reported as new patients on the same day. Their story is told as a Family Case Study in the Appendix. He had waited at least two years after being first recommended to Green Pastures by a neighbour who is an LCP worker. He came to the hospital with his son two weeks after another son had died there.

As a Brahmin priest he had made a vow to the gods but had not yet been able to fulfil it. He believed his condition was a curse, written in the stars. He came with the hope that medicine would help his problems. Both he and his son continued treatment regularly.

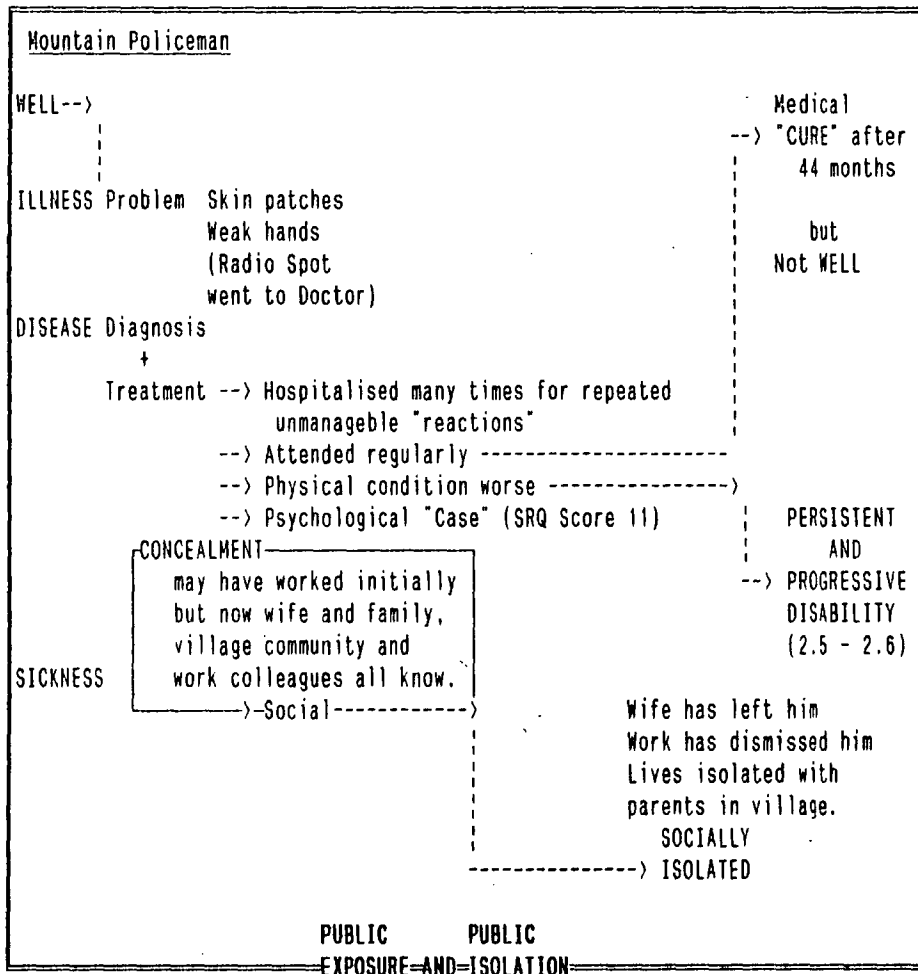
Even though his village neighbours know about his diagnosis his social status as a Brahmin priest is such that they say nothing. They wait and see. They may not isolate him even if his disability and deformity are permanent.

ILLNESS CAREER FOUR



This lady was ill for almost a year before her husband consented to seek help outside the village. By that time her feet and legs were so swollen that she could no longer walk or work. He took her to Pokhra, to a doctor who referred her to Green Pastures Hospital. There he left her and went off with another woman. He is in another part of the country now with his new family. He was the patient's third husband and not of her caste. She now lives alone, in public isolation. Her situation is precarious as she has no land to live off. As a woman who has gone against the mores of her society in marrying out of caste, she does not enjoy community favour. She lives off savings and what work she can get. In these circumstances a finding of psychiatric "caseness" is not surprising. Her depression goes on and her situation has little hope of change. She enjoys a medical "cure", has no deformity, but does not have her social integrity.

ILLNESS CAREER FIVE



In this case we see a tragic irony. The medical "cure" is pronounced in the presence of this man's physical condition becoming progressively worse throughout his treatment. He was in hospital for 22 out of the 44 months it took for the disease process to become inactive and his smear to revert to negative. He was regular and compliant. At interview he asked us: "Why am I getting worse? I have done everything the doctors told me."

He had repeated severe "reactive" episodes which the medical staff of this referral hospital were helpless to control effectively. The medical officer in charge told me he had used all the drugs he knew about, yet could not arrest or reverse the disabling process. The medical treatment of *complications* is not always adequate.

This man used to be supremely physically fit. He was a disciplined professional man with a future and a career. Now he

has extensive disability (both eyes, both hands and both feet are involved). He is still proud, well groomed. But his family has broken up, his wife has left him and his career is finished. He is medically "cured" but

The above five examples illustrate the variations in the illness careers of people who continue attending clinic. The following series are of those who stayed away and one who had been absent but came back again. They again present variations but show clearly the central place of the concealment cycle. Who knows about their condition is an important question.

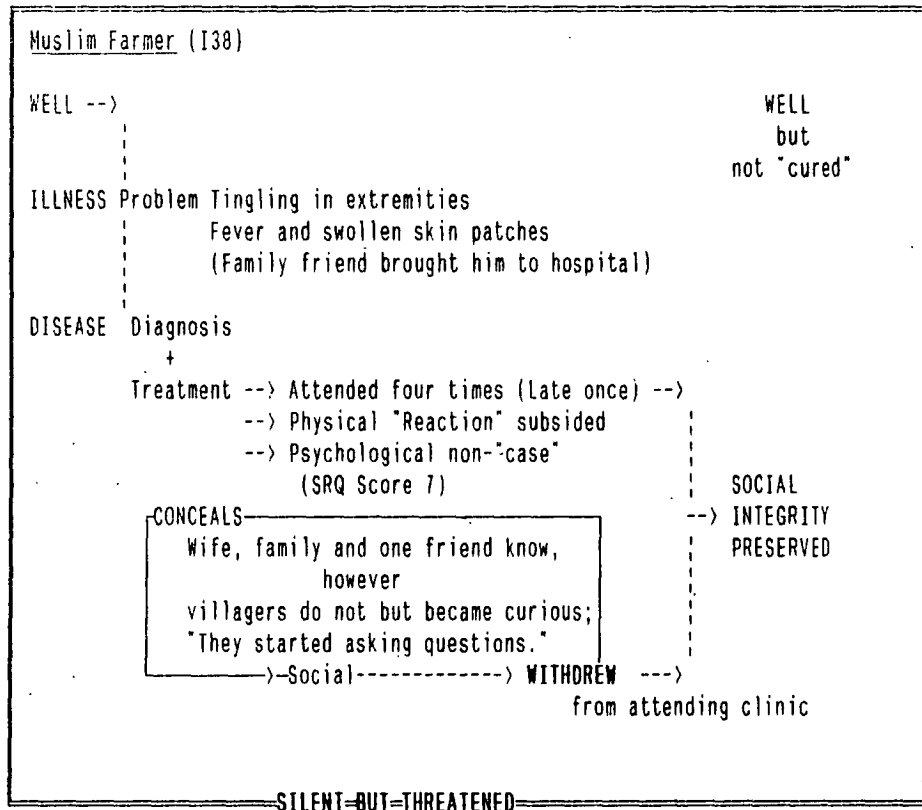
ILLNESS CAREER SIX

In this case the person withdrew from clinic attendance after a series of events, similar to those found with I39 above, which seem to have combined to lead to this decision.

1. The medication causes black skin discolourations. the presence of which "triggered" curiosity of community members. "They started asking lots of questions." When the the medicines are stopped for a few months the skin colour returns to normal.
2. He had been told to take the medicines during the day and after a meal. When the Muslim festival of Ramadam came round he could not do that because he was required to fast during the hours of daylight. Consequently he did not take the medicines for a month.
3. He had been late once and been received in a disrespectful and demeaning way, had to pay a fine and was "warned" and shouted at for being late. While he was at the clinic he had also witnessed the reception of others who were late for their appointments. Next time, when he could not go on time he did not wish to have that repeated so he did not go.
4. His physical problem (illness) was resolved although he still had some tingling in his extremities. The research assistant formed the opinion that he was likely to continue medication, but without the "black" medicine and from another place. His

friend who had taken him to the hospital was a trainee health worker and had urged him to go on taking the drugs.

ILLNESS CAREER SIX



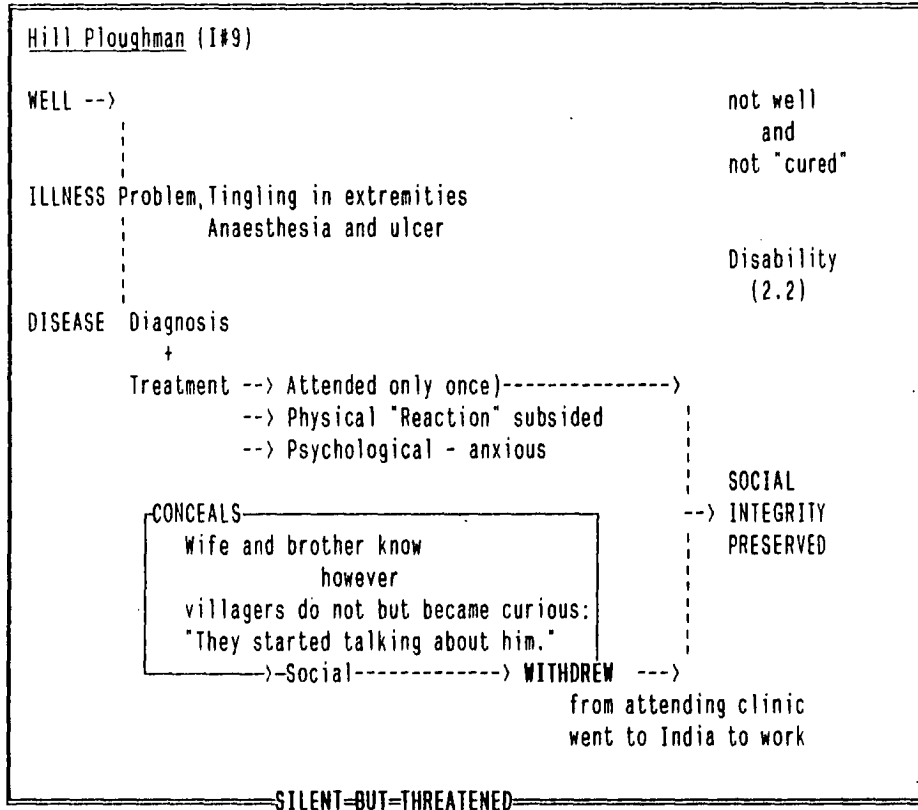
His withdrawal from the clinic had the effect of deflection of public curiosity, and of restoring the skin to normal colour. It is interesting to speculate in this case whether his status in his community was secure enough to have withstood public exposure as a Kushtharogi. He is a Haaji, having completed a pilgrimage to Mecca. However answers to questions about the specific attitude to Kushtharog of Muslims and other small minority groups in Nepal await further study.

ILLNESS CAREER SEVEN

In this case his problem got a bit better but because of his disability he began to eat with a spoon. In his village where everyone eats with their fingers such an unusual practice "triggered" talk. To avoid confrontation he decided to go away (for a legitimate reason) to protect his family's social standing. If he had been labelled Kushtharogi it is unlikely

that suitable marriage partners could have been found for his children.

ILLNESS CAREER SEVEN

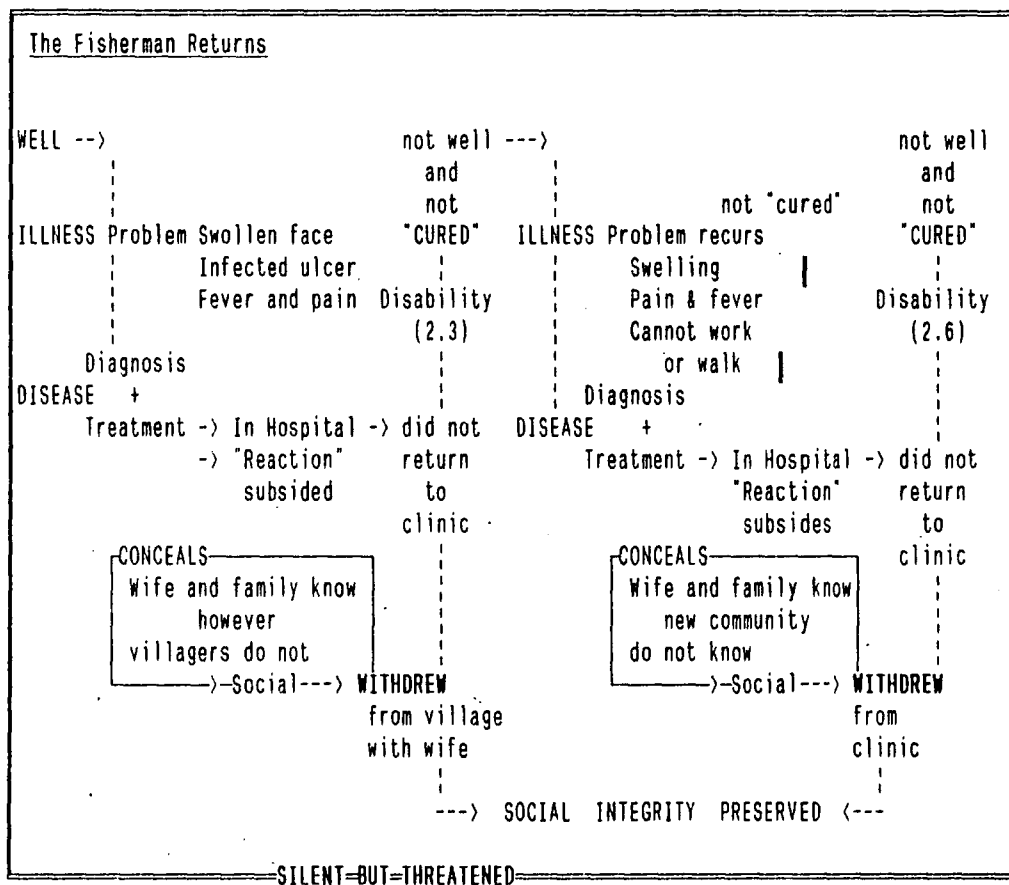


From what his wife told the research assistant, it is possible he is still taking medicine while in India as he had asked for his hospital card to be sent to him there.

As was the case with Sri Pariya, withdrawal from clinic attendance may not be an indication that a person has actually stopped taking medication for the physical problem. If the problem is still giving them trouble or if a new problem occurs they seem to seek the medicine anyway.

This point is illustrated in this last illness career of a man who came back. This last case is of particular interest. It illustrates a phenomenon noted in Thailand by Neylan et al. (1988) who found that some patients perceive their illness as separate, distinct acute episodes of illness, not as flare-ups of

ILLNESS CAREER EIGHT



a long-term chronic illness. Like them, this man has had two episodes of very severe reversal reaction for which he needed at least three months in hospital. The reactions subsided. While he was in hospital he received regular MDT, so his disease would no longer be infectious. But once released from hospital he did not return, perhaps because he was no longer ill in his terms.

Many patients do not have the concept that their disease is a chronic one which only slowly gets better. The notion of chronicity and the time needed for positive smears to change to negative is not just difficult for this man. There are many patients who are no longer ill in their terms but who are told to keep coming for treatment because they are not yet "cured".

For this man there may be other factors involved in his not coming to the clinic. He is low caste and poor, needs to fish to live, travelling round the country to various rivers. Regular travel to the clinic may not be a possible part of his life.

The research shows that other influences operate in the lives of these people which affect their decisions and ability to sustain their treatment choice, even when they are unable to offer "rational" western explanations. This suggests that Kleinman's model is inadequate because of its undimensionality to explain a multi-dimensional social phenomenon.

Kleinman (1980:114) postulated that the closer patient explanations are to those of the health workers, the more likely they are to be compliant (in this context attend clinics). The research data suggest that the reality is far more complex. The patients may comply in an instrumental sense without adhering Effectively to the over-arching belief and value systems of western medicine. Belief about the origin of illness may not be as closely or directly associated with either treatment choice or sustaining that choice as is required in leprosy treatment.

From the explanations and experiences of people with leprosy presented in this chapter, it is clear that in Nepal leprosy is far more than a biological infection to be cured by antibiotics. The physical, emotional and social consequences of leprosy have been noted. The meeting of two worlds shows up differing expectations of treatment and concepts of cure.

The relationship between the re-appearance of physical problems to patients returning for treatment after long absences is noted. However the effect of this re-appearance on the concealment cycle is not known.

It is also noted that the practice of negative reinforcement - the fine and the berating of late and long absent patients - had a negative effect on further continuation of treatment. Because the implementation of such sanctions for patients who were late for appointments does not fit into a health promotion model of service delivery, or a holistic approach to care, and because it is shown to have a negative effect on clinic attendance a change in this practice is recommended.

The central importance of the concealment cycle in patient illness careers is also shown in this chapter with its relationship to withdrawal from clinic when people with leprosy attempt to preserve their place in society.

In the next chapter (12) the threads are drawn together in a comprehensive summary and conclusions.

CHAPTER 12: SUMMARY AND CONCLUSIONS

This research set out to examine the "problem" of patient compliance in a leprosy control project in the socio-cultural context of Nepal. Community beliefs about leprosy have been presented against the backdrop of the general medical system of Nepal which is a complex mix of personalistic and naturalistic notions of the origin of illness and which increasingly accommodates scientific medicine as well. After a close examination of patient beliefs about the origin of their condition, which were found to not relate closely to decisions about clinic attendance, the focus of the study was directed towards the socio-cultural world of these people.

This examination of leprosy in its cultural setting has revealed aspects of the socio-cultural beliefs and practices in Nepal which point to confusion about ideas of what leprosy is and what it means to be cured, and which have association with patient drop-out from clinic attendance. The significance of these findings is not limited to the "problem" of compliance in leprosy control, nor to Nepal alone. There are broader implications for approaches to planning and implementing services and training programmes for staff, as well as for health education programmes for the public and patients in Nepal and beyond.

RESEARCH FINDINGS IN RELATION TO THE STUDY PROPOSITIONS

This research has examined two general propositions set out in Chapter 4. Firstly, that a relationship exists between patient compliance and disparities of explanation held by patients and their practitioners. Secondly that the social meaning of leprosy impacts patient compliance.

The research findings do not bear out the first general proposition. After an examination of the explanations of leprosy given by various categories of patient using the data available through this study, there appears to be no relationship between disparity of explanation and patient compliance as expressed in clinic attendance. In Chapter 11 it was shown that there was

little difference between the notions of causation of leprosy among the various categories of patients studied, namely those regularly attending clinic, those who had absented themselves and remained non-attenders, and those who had returned to clinic after a long absence. This is a significant finding as it flies in the face of usual medical thinking about what needs to be taught to patients about their condition. For leprosy in particular it seems to be thought that if patients understand that their disease is caused by a micro-organism and that that micro-organism will be killed by the drugs then they are more likely to be compliant with treatment. In relation to the patients who returned after long absences, it seems to have been a new or reappearance of a problem which brought them back to the clinic. Perhaps it was knowledge that the clinic could probably help rather than knowledge of the origins of the problem itself. In one way this finding is not surprising as studies in the past have shown no direct relationship between knowledge and health behaviour. Aagard-Hansen (1991) discusses this point and even asks why we need to teach patients about their condition at all. Because the behaviour studied in this thesis is, as Mull et al. (1989) put it, complex and culturally constrained, it would be surprising to find a strong relationship between action and knowledge alone.

The research evidence does, however, bear out the second general proposition, that the social meaning of leprosy does have an impact on patient compliance. More refined and focussed hypotheses may be developed by others on specific items building on this work. The findings of this research in relation to the five hypotheses suggested from this general proposition are discussed in this chapter. The first three are inter-related.

Hypothesis 1: A relationship exists between compliance expressed in clinic attendance, and cultural definitions of sickness and health.

Hypothesis 2: Socio-cultural as well as medical meanings of leprosy in the context of Nepali beliefs impact on patient compliance and other aspects of patient behaviour.

Hypothesis 3: Cultural concepts of "sickness" and "disease" are reflected in patterns of community social sanction such as social separation of Nepali leprosy patients, and these also impact on patterns of compliance and non-compliance.

Evidence from the community survey (Chapter 8) and patient interview data (Chapters 9 and 11) appear to support these hypotheses. Indications were found that there is a strong expectation among both the general public and leprosy patients of social separation for those with Kushtharog. Many patients were found to be keeping their condition secret because of this expectation, in some cases even concealing it from their immediate families. In the event of family or neighbours asking persistent questions about their condition several patients were found to have withdrawn from clinic attendance. The **Concealment Cycle** described in this chapter, among other things, relates social identification of the "sickness" leprosy with patient withdrawal from attending clinic.

Hypothesis 4: As well as notions of medical cure, the concept of social health and "cure" of leprosy in Nepal, as expressed in social integration and re-integration in society, are reflected in patient careers and compliance problems.

The findings presented in Chapters 9 and 11 are drawn together in this chapter with a discussion of the overlap and distinctive aspects of Nepali traditional versus biomedical notions of leprosy cause and cure. This discussion points to the important place social concepts hold in the meaning of leprosy in Nepal.

Hypothesis 5: Ethnomedical and cultural considerations must be taken into account in any health education programme if patient compliance and "medical" as well as "social" cure are to be achieved.

Without the ethnomedical and non-ethnocentric approach adopted in this research, the **concealment cycle** and the important finding of contradictory understandings of the physical, psychological, social and metaphysical meanings of leprosy between the Nepali

traditional and western medical thought, presented in Chapters 8, 10 and 11 and discussed in this chapter, would not have come to light. These issues are of major importance to health education.

This chapter, therefore, draws together the threads of the thesis, pointing out the interactions and contradictions between the scientific and Nepali traditional medical models in relation to health, illness and cure in general and in particular in relation to leprosy. An "ideal type" construct relating to patient illness careers is proposed. The centrality of the concealment cycle model to the preservation of patient social integrity and the place of clinic drop-out in the model are discussed. Thus significant socio-cultural conventions related to leprosy in Nepal are summed up.

The conduct of this research and the models developed as a result represent an example of the importance of an ethnomedical approach to a cross-cultural health problem. Without such an approach the general use of global models discussed in Chapter 2, such as the Health Belief Model (Becker 1974) and the PRECEDE/PROCEED Model (Green and Kreuter 1991), would not uncover such significant socio-cultural mechanisms. Such an approach both recognises and accepts the reality and validity of the medical system and definitions of the particular cultural setting suggests that this represents an important adjunct to these existing health belief models which may have been overlooked. (See Figure 2:2 for HBM and PRECEDE/PROCEED models.)

NEPAL TRADITIONAL AND SCIENTIFIC MEDICAL MODELS

In Chapter 7 the complex medical system of Nepal is described and discussed in some detail. It is clear from this presentation that the "world" of scientific medicine differs considerably from the traditional Nepal medical model. This difference is represented in Figure 12:1 (see over).

Health and illness according to these models

Scientific medicine sees health or wellness as equilibrium in the physical (bodily) and psychological areas and operates only in

these. It deals with illness as dis-equilibrium in these areas. Cure brings about restoration of health in these terms.

In contrast **traditional medicine in Nepal** sees health or wellness as holistic harmony and deals with every area of the whole. Illness is conceived of as imbalance originating anywhere in, and affecting any or all areas of, the whole. Cure means restoration of balance in the whole. Dividing of the "whole" into categories is not in keeping with the Nepal traditional model, in which the seen and unseen flow progressively into one another.

IN TRADITIONAL NEPALI AND SCIENTIFIC MEDICAL MODELS:
*Health and Illness Originate and are Dealt with
in Different Arenas*

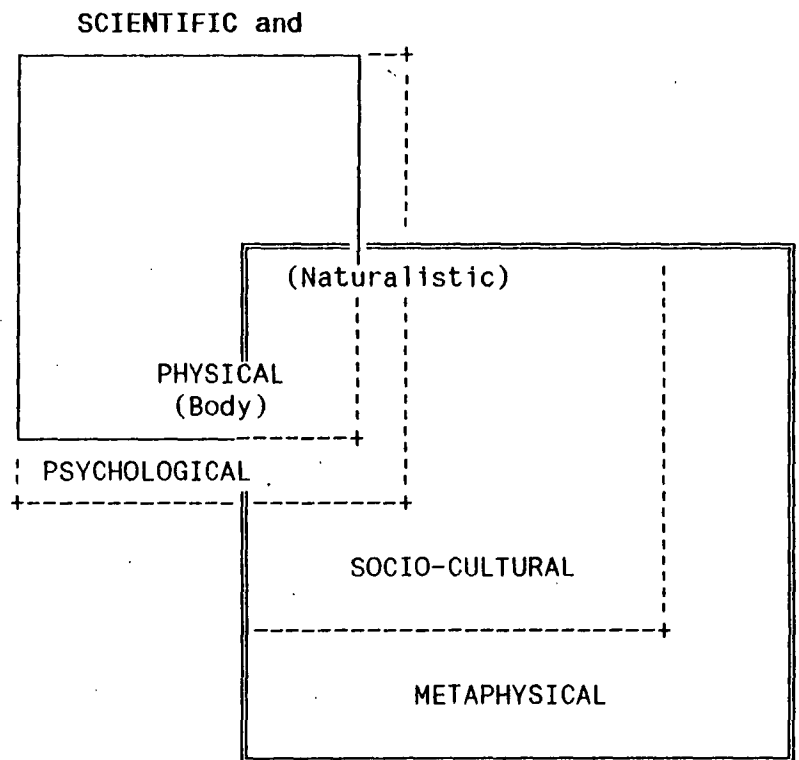


FIGURE 12:1

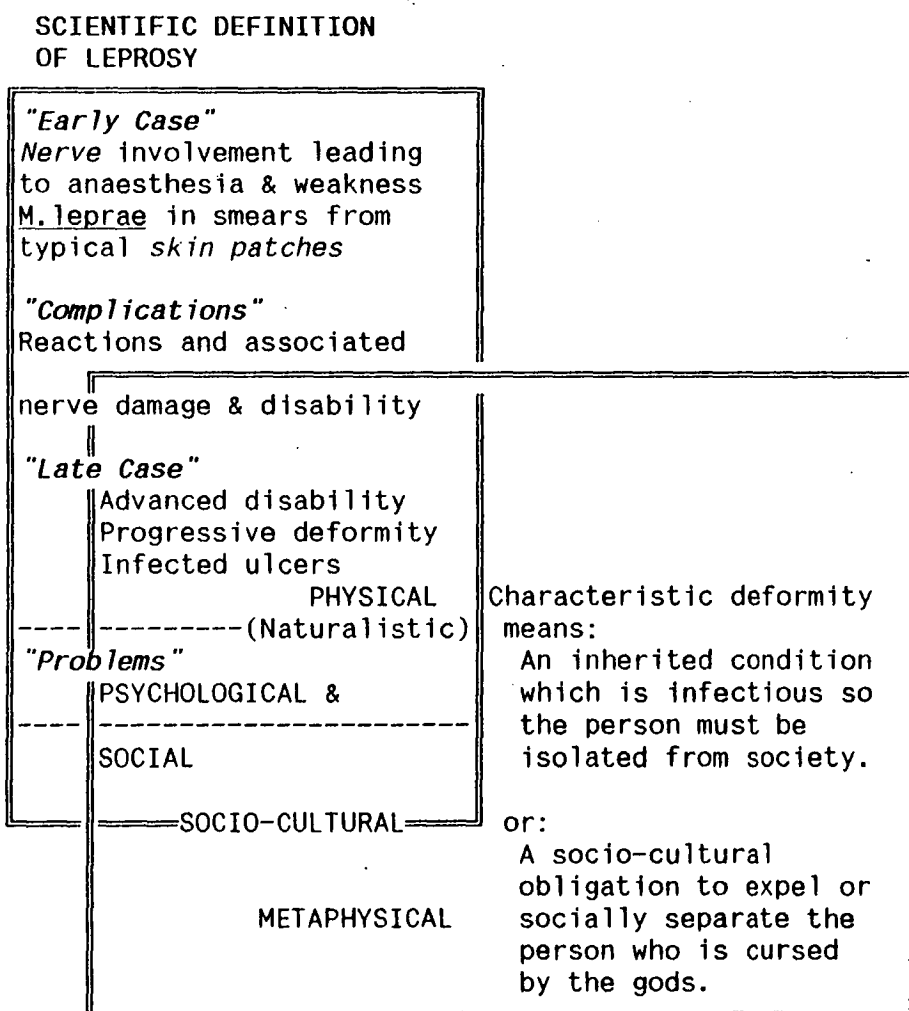
In Figure 12.1 we see that the socio-cultural aspects form a smaller part of the concerns of the scientific model, and the physical and psychological form a smaller part of the metaphysical and socio-cultural concerns of the Nepali traditional medical model.

Leprosy in Terms of These Models

In Nepal the traditional view of leprosy is as Kushtharog and this is a holistic concept. Figure 12.2, shows that physical signs are recognised "late" according to scientific medicine, that is, only when disability and deformity are obvious. For Nepali patients a psychological response to a diagnosis of Kushtharog is often depression because, according to socio-cultural practice, people with Kushtharog must be separated or expelled from communities (social death). These elements are integral to the whole, the social meaning of the "sickness" of Kushtharog reflects the over-arching nature of metaphysical belief, the concept of Kushtharog as being fated or a "curse".

LEPROSY IN TERMS OF NEPALI TRADITIONAL AND SCIENTIFIC MEDICAL MODELS:

Definitions of Leprosy Overlap



NEPALI TRADITIONAL MEDICAL DEFINITION OF LEPROSY KUSTHAROG

FIGURE 12:2

By way of contrast scientific medicine sees leprosy primarily in terms of *physical* manifestations, conceptualising it as being micro-biological and immunological in origin. To scientific medicine leprosy can be recognised very early, that is when the effects of the disease process on the peripheral nerves and skin are just beginning. Doubtful diagnosis may be confirmed by biopsy. Thus scientific medicine recognises "early cases" while the Nepali traditional system does not. Scientific medicine sees leprosy as being *complicated* by immunological reactive episodes and physical disability which may or may not be permanent and progressive. Leprosy is also seen to give rise to psychological and/or social *problems* for some. These are not seen as part of the disease and are not addressed by many programmes except in terms of prevention.

ACCOMMODATION

Traditional Nepal society deals with new ideas and practices by accommodation, by incorporating them into their existing "world view". It seems, therefore, to hold beliefs side by side which to the western mind seem contradictory or even mutually exclusive. This was illustrated from the community survey of views about the origin and possible cure of leprosy. Most people reported a combination of notions of causation which reflect an *inclusivist* rather than an *exclusivist* approach. The effect of the accommodation of two scientific-based beliefs - that *germs* cause leprosy, and *medicines* can be used to treat it - with traditional ideas, was shown to increase community expectations of cure. Here accommodation is seen in action. However, the inclusion of these same beliefs seems not to have a significant effect on the strong community expectation that people with leprosy are or should be socially separated.

These points are represented in Figure 12:2 (above) which shows the areas of overlap and areas of distinction between the scientific and Nepali traditional definitions of leprosy.

SOCIAL SEPARATION

The expectation of social separation seems to be so strong that most people who are diagnosed as having "leprosy" - to them "Kushtharog" - are intent on concealing it. The technique of concealment was described by Miller (1990). He found it operates in areas of rural Nepali society where matters are of a personal nature. It is found to be operating in relation to leprosy. In this thesis the process associated with leprosy patients' efforts to preserve their social integrity is called the **concealment cycle**. For some people this process seems to be cyclical while for others it is linear.

THE CONCEALMENT CYCLE

In Nepal, after the medical diagnosis of the "disease" of leprosy, the social integrity of leprosy patients may be preserved, threatened or disrupted depending on who knows about it and what they do about that knowledge. This concept is represented in Figure 12:3 below.

In an effort to preserve social integrity the **concealment cycle** is used. The persons keep their diagnosis secret as long as possible, even from their spouses and family circles. The technique of **concealment**, keeping silent combined with using "stories" to deflect discovery, is found to be operating in relation to leprosy as it does for other private matters in village life. People appear to begin to feel **threatened** with exposure when "They start asking questions." Various events or changes seem to act as "triggers" to the curiosity and questioning of village neighbours, and precede actions that the persons may take in an attempt to preserve their place in village society - their social integrity.

Some "triggers" noted from patient interviews were:

1. The regular but necessary absences of the person from the village were noted and commented upon.
2. The person started doing something different, like wearing shoes or eating with a spoon.

3. An unusual event occurred such as a letter coming from the hospital for the person.
4. Their skin gradually became darker or "black".

**CONCEALMENT CYCLE: *Used by
Leprosy Patients in Nepal for
Preservation of Social Integrity***

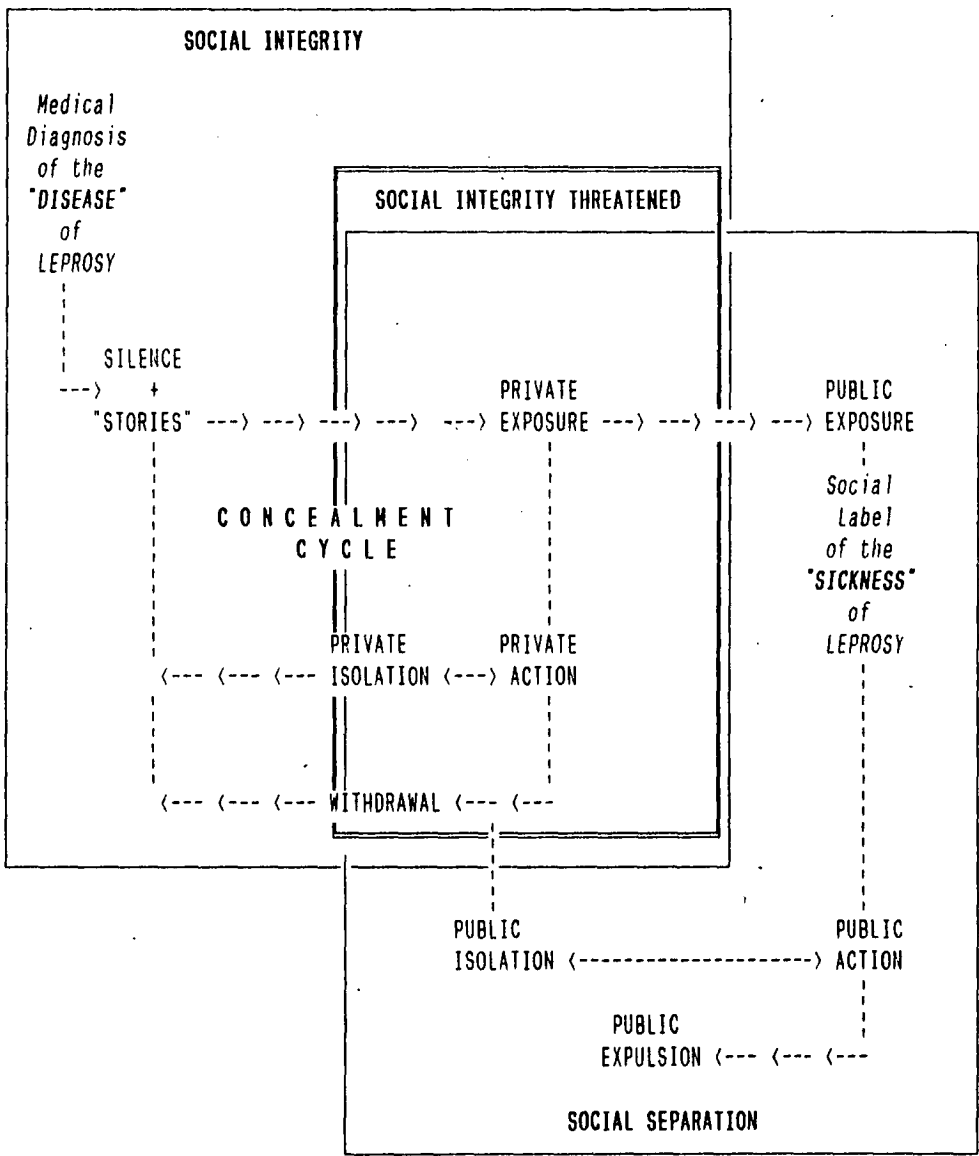


FIGURE 12:3

Withdrawal

When patients feel that their social integrity is threatened they may act privately and swiftly in order to preserve it by withdrawing. Withdrawal may involve the following actions on the part of the person with leprosy who feels their social integrity is threatened:

1. The person may stop going to the clinic regularly.
2. They may leave the village, taking the family, setting up home in another community in which case they may seek medicine from another place if their problem persists.
3. They may leave home alone to look for work in another community. Some go to India for work.

All these actions are "legitimate" in the eyes of the community and potentially leave the social standing of the person and their family intact. They are therefore able to return to silence. This is the first part of the cycle.

Gender differences

In Nepali village society the options open to women in relation to this model for withdrawal and return to concealment are more limited than those of men. Women are in dependent relationships in the family circle. It would be unlikely, for instance, that a woman could leave home alone, seeking work in another place, and have it regarded as legitimate by her community. Such action would be likely to precipitate much more public curiosity and slander than if a man did it. The particular difficulties faced by women in relation to safeguarding their social integrity would warrant a study of their own.

Public exposure

Public exposure seems to be signalled when "They started to talk about me"; that is the village people say nothing to the person's face but gossip about him behind his back. Miller calls this **public silence - private slander**. The patient usually comes to hear of this talk through a friend. This stage of imminent exposure may go on for a long time as Nepali village society is interdependent and there is usually a reluctance to move from private slander to open conflict which would disrupt necessary harmony. They often "wait and see". For some people with leprosy this provides the opportunity to continue and complete treatment and to obtain a "certificate" from the hospital and so on. This may be sufficient to enable some communities to agree to continue to "wait and see", keeping the person in their midst. Alternatively at this stage the person may withdraw from the village and resume

concealment in another community but alone. But by this action their family in the village is left in a better social position than if they stayed. For some, however, public exposure occurs and the consequences follow.

Social sanctions: Public isolation or expulsion

Once public exposure takes place and the social label of the "sickness" of leprosy has been applied, it is the practice that the person is socially isolated or expelled. In some communities social isolation may only consist of being required to sleep and eat separately but still within the family home. In other cases it may mean that the patient is required to live in a separate shelter in the village, for instance in a cow shed. In the extreme case the person may be sent away from the village all together. This last form of social separation is very serious as the person is removed from the usual means of physical and economic support. It is social death. One woman interviewed in the field research provides an extreme example. She had been living in a separate shelter for 18 years. She had been fed and clothed and in turn had helped with herding the cattle. After her husband's death she was sent away by her daughter-in-law who refused to feed and cloth her any longer. What she was really telling her was, "Go and kill yourself!" This particular woman had been on her way to "jump into the river" when she was met by staff from the leprosy project. Another example is of a man who was interviewed. He had been an itinerant ploughman dependent on his neighbours for work and thus his living. After public exposure he had been refused work by all his neighbours, a not too subtle form of public expulsion. His story is found in the Case History Appendix.

Withdrawal from attending clinic in the concealment cycle

In this model the place of withdrawal from attending clinic is as an occasional part of the process employed by patients of concealing their leprosy and thus preserving their place in society through withdrawal. The model, in the nature of models, represents an ideal type logical construct and as such does not represent the whole story in every detail for each person with leprosy in Nepal. It is a heuristic device for representing

sequences of events and interactions and as such makes further progress in understanding the world of the Nepali leprosy patient than has been made up to the present.

CONCEALMENT CYCLE IN RELATION TO PATIENT CAREERS AS "IDEAL TYPE"

This model is a construct for the purposes of this research. It is important to clarify what it does and does not represent. The model is formulated as a precise concept of a unique piece of reality. It stresses the "typical", distinct elements relating to leprosy patients in Nepal and their experience of leprosy as told to the researchers in this study. It does not sum up the traits common to all leprosy patients in Nepal. Rather it emphasises the viewpoint of patient behaviour in relation to concealing their diagnosis. It arranges, through synthesis, the discrete elements of the illness career into a unified analytical construct. As Max Weber defined it, the "ideal type"

... is formed by the one-sided accentuation of one or more points of view and by synthesis of a great many diffuse, discrete, more or less present and occasionally absent concrete individual phenomena, which are arranged according to those one-sided emphasised viewpoints into a unified analytical construct. (Freund, 1968:60 quoting Weber)

The model is not trying to say that all patients follow these paths or that the model includes all the individual variations in experience on the career path, but that some sequences are much more likely than others. The illness career patterns in Chapter 11 show both conformity to the path and some individual variations. The model helps us to understand concepts used by the researcher in this study and their relationship to the leprosy patient's social reality.

DISCUSSION OF MODELS: FURTHER REFINEMENTS

In Chapter 2, two previous models were discussed which relate particularly to this study (Figures 2:1 and 2). These are the Health Belief Model (Becker, 1974) for predicting health behaviour and the PRECEDE/PROCEED Model (Green and Kreuter, 1991) for planning health education and promotion. The Health Belief

Model has been used extensively and successfully in many contexts, and many people have added to it or suggested new and alternative models. Examples include social learning theory (Bandura, 1982), the theory of reasoned action (Ajzen and Fishbein, 1980). These elaborations show the continuing difficulty researchers have with finding an adequate model for explaining, understanding and predicting patient compliance.

A cluster of "modifying factors" has been added to the Health Belief Model. The PRECEDE/PROCEED Model, which to some extent was built upon the Health Belief Model, has also been added to or enhanced over the last decade. Both the "modifying factors" of the Health Belief Model and the large concept of "Environment" which is added to PRECEDE incorporate, but do not spell out in any detail, the area of enquiry of this study, namely the socio-cultural context of health behaviour.

The models of patient illness career patterns and particularly the concealment cycle represent an added dimension to these global but culturally relative models. In terms of the above models this thesis provides examples of culture-specific modifying factors or negative reinforcing factors. The thesis approaches an understanding of behaviour which acknowledges and accepts the different world views in the cross-cultural setting and attempts to move across into the world view represented by the traditional medical system of another culture. Through this ethnomedical approach, insights gained into the tangle and complexity of the definitions of leprosy in the Nepal setting, and into the social sanctions faced by leprosy patients in Nepal and avoidance mechanisms used by them, add depth to the global models mentioned above. Such global models need to be applied in cross-cultural settings with great caution and with recognition of limitations which may apply.

The "boxes" within such models which group together "background" variables such as beliefs, values and normative considerations under headings such as 'socio-psychological' or 'behavioural causes' now need 'unpacking' and assume greater importance in the models, as this thesis demonstrates.

THE CONCEPT OF "CURE" IN LEPROSY IN NEPAL

The difficulty of defining "cure"

There are other insights gained from this study which have significance for planners and educators and for patients. Because of the different arenas of operation between scientific and traditional Nepali medicine, there is confusion and even conflict when it comes to the notion of "cure" of leprosy (Figure 12:4). For both traditional Nepali society and scientific medicine there are difficulties with the concept of cure in leprosy.

To traditional Nepali society the concept of cure of Kushtharog (leprosy) is foreign. Ancient Aryuvedic medicine does have a host of remedies for it (see Appendix pp. 23-31). One or two of these were taken by mouth and were said to be effective on the course of the disease in a general way. The rest were mainly topical, to be applied to the outside of the body, for skin problems, wounds and so on. One ancient remedy was the basis for an earlier, pre-antibiotic, medical treatment of leprosy, Chaulmoogra Oil. This was known about at the time leprosy was first described in ancient Indian literature around 600 B.C. (Jopling 1984:4). It was said to have some beneficial effects but was, however, not really effective (Thangaraj and Yawalkar, 1986:55).

Once a Kushtharogi is recognised as such his physical disability and deformity are already present and he may also have infected ulcers. These are all features of "late cases". The ulcers and wounds can be treated and healed but the deformity cannot be completely reversed even by scientific medicine. It usually gets progressively worse even in the presence of good self-care on the part of the person affected. Once the label of Kushtharogi has been applied to a person there seems to be no way back from social separation either. It is easy to understand why Nepali traditional society does not overwhelmingly expect that Kushtharog will be cured.

Research findings from the community survey showed 54% of respondents said "Usually" and 45% held serious doubts about

cure. Kushtharog (leprosy) is seen as a disabling disease. The Kushtharogi is doomed to having no hands and feet. In the community survey 91% equate ulcers with it, 92% think it is contagious, 64% regard it as inherited, 63% associate it with germs, 55% with fate and the stars, and 44% of women regard it as a curse of the gods. Social isolation is expected by 78% and separation by 73% of this sample. Just over half (54%) say it is usually curable; however this is reduced to 26% if they see fate as its origin and a religious ceremony as its cure. The percentage who expect a cure is 65% of those who see it as caused by germs and cured by medicine. Almost all (93%) of those who see it as originating from fate and being a curse believe it must be isolated or separated. This percentage is reduced among those who see the cause as germs and the cure as medicine. They say it must be isolated (77%) and separated (72%). It remains the reality that three quarters or more of this community expect social sanctions to be applied to Kushtharog and almost half entertain serious doubts about the possibility of cure. This present reality for patients translates into their having a serious psychological burden and carrying a heavy secret which they conceal, in many cases even from their intimate family.

In Nepal the message of scientific medicine that "leprosy is curable" (Kushtharog niko huncha) is thus somewhat misleading to ordinary people and a contradiction in terms. In particular it is not believed when the person - said to have been cured - is a leprosy patient (Kushtharogi), who has completed the necessary treatment but who still has deformity and especially has ulcers. They still have Kushtharog!

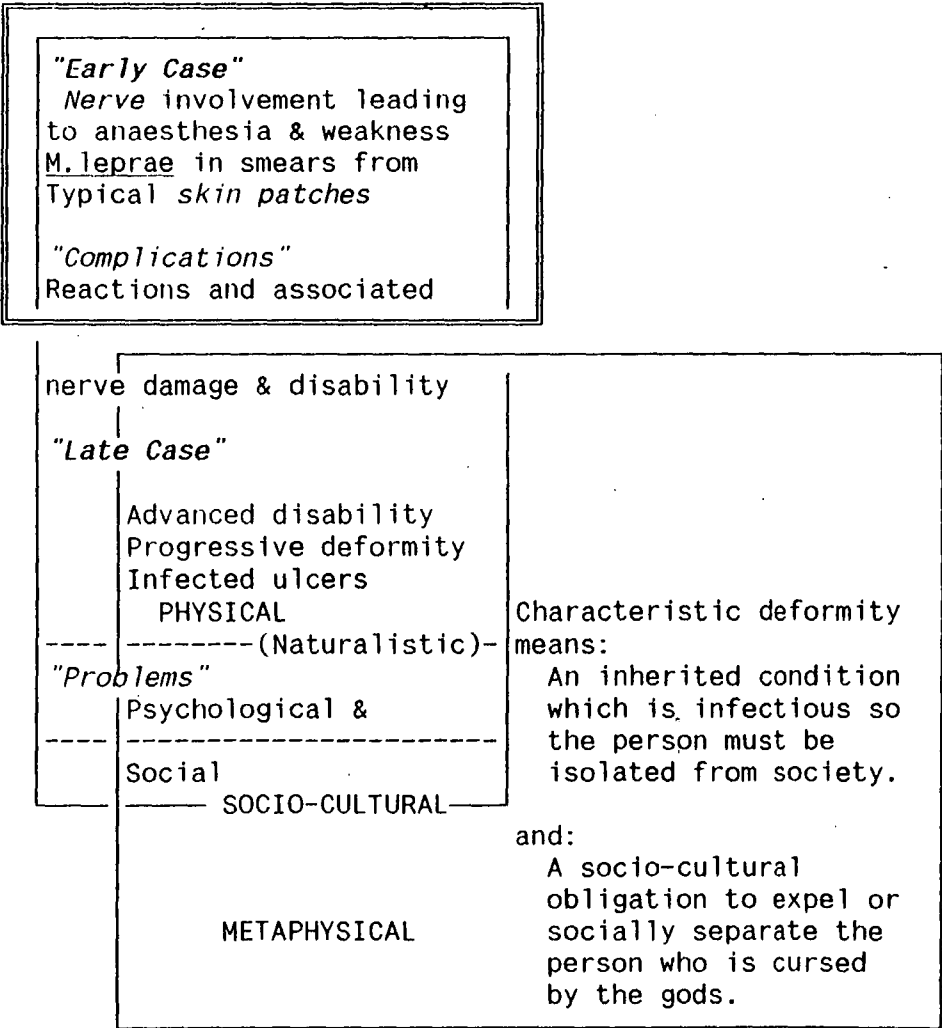
Neither is there a concept of social "cure" for the socially separated or expelled Kushtharogi in traditional Nepal society even when declared "medically" cured.

The scientific medical definition of "cure" of leprosy embraces only the physical and that within the body. Leprosy is medically "cured" when the micro-bacteria are no longer detectable and when the "disease process" is no longer active.

To scientific medicine it is logical that even though there is residual disability, subsequent progressive deformity only occurs if the patients are "careless" and is preventable if they care for themselves "properly". This logic is unfortunate because it blames the victim and disregards the progressive pathology of neuritis, contractures and tissue absorption which make deformity inevitable for some people; even long after treatment has been completed. It also tends to approach the problem of after-care from a negative perspective.

CURE OF LEPROSY
 IN TERMS OF NEPAL TRADITIONAL AND SCIENTIFIC MEDICAL MODELS:
No Overlap

EXTENT OF SCIENTIFIC OR MEDICAL
 "CURE" OF LEPROSY



TO NEPAL TRADITIONAL MEDICINE KUSHTHAROG is
 NOT CURABLE

FIGURE 12:4

Using the graphic presentation of the definitions of leprosy from Figure 12:2 the extent of medical or scientific cure of leprosy is shown in Figure 12:4 above by double boxing.

As indicated in Figure 12:4 the concept of medical "cure" does not include the reversal of the "complications" of physical disability or deformity. Nor does it include the psychological and socio-cultural "problems" which a holistic view would encompass. Some programmes in Nepal do make some attempts to help people with their "complications". For example patients with reactions are hospitalised and treated vigorously, active reconstructive surgery programmes are conducted at referral hospitals, the psychological needs of some patients are focussed on. The SES Department at Green Pastures Hospital for example looks to assist patients who are experiencing social (and economic) "problems". However these "problems" are not seen as part of the "disease" and are not included in the concept of "cure". Scientific medical "cure" of leprosy is claimed to have taken place even in the presence of disability, permanent and progressive deformity and psychological and social problems. Medical "cure" of the disease does not effect a social "cure" of the sickness, a restoration of previously held social roles and status.

A Nepali "cure" of leprosy? Practical implications of these concepts/findings?

For a concept of "cure" to "work" in Nepal it would have to embrace and reinstate to harmony and integrity each arena of the definition held by Nepali traditional society; in other words it should flow through the whole. This concept is represented in Figure 12:5 below which uses a variation of the model of definitions of leprosy (Figure 12:2) with the usual scope of scientific medicine limited to the physical and the psychological arenas. Concepts used in the Illness Career graphics such as medical cure, psychological caseness, social integration, are included here together with the metaphysical dimension.

There are three main possibilities which could be considered when making use of these findings in planning health education of the public about leprosy.

Firstly, to aim to use the knowledge of "accommodation" to have the notion of "early case" included in the Nepali notion of Kustharog could increase the expectation of cure even more. As was shown in the community section, having scientific notions added into traditional notions has increased the expectation of cure for those people. However there may be undesirable effects as well. In the community survey it was found that the scientific notions added into existing notions had no effect on the public expectation of isolation or social separation. As was discussed in Chapter 8, the expectation of social separation is so strong that the change of the law in 1963 has not yet been strongly reflected in the cultural practices of Nepal. It could lead to the labelling as Kushtharogi people with "early" leprosy who previously would not have been so recognised. It may therefore not be helpful to use the "accommodation" in this way.

Secondly, is there a possibility of asking Hindu religious leaders to consider having a suitable footnote included in future editions of the Swastani Brad Kota? Would this help to eventually change cultural beliefs and practices? Such a footnote could perhaps say that modern scientific medicine can identify signs which if untreated lead to Kustharog, but if treated the development of Kustharog can be prevented.

Thirdly, to expand the scope of the scientific approach to care and cure of leprosy to encompass the social and metaphysical arenas would face the reality of Nepali definitions. Is there some way, in collaboration with traditional leaders and healers in Nepal, of using a concept of a "certificate" and "ceremony" or rite of passage which would do the same for a leprosy patient as the PATITAA PURJU and PRAATASCIT do for the ritually polluted? (see Chapter 9). If these were to be added to the routine of release from control, cure of leprosy, "accommodation" would be brought into play, thus making use of the nature of Nepali traditional notions. These may be appropriate ways to, over

time to enhance the social acceptance of people with leprosy. They may be prepared to "wait and see" rather than expel, and to re-integrate them into their previous social positions.

A NEPALI "CURE" OF LEPROSY?
To "fit" in Nepal Traditional Society a Concept of Cure of Leprosy Needs to Operate in Each Arena of the Whole.

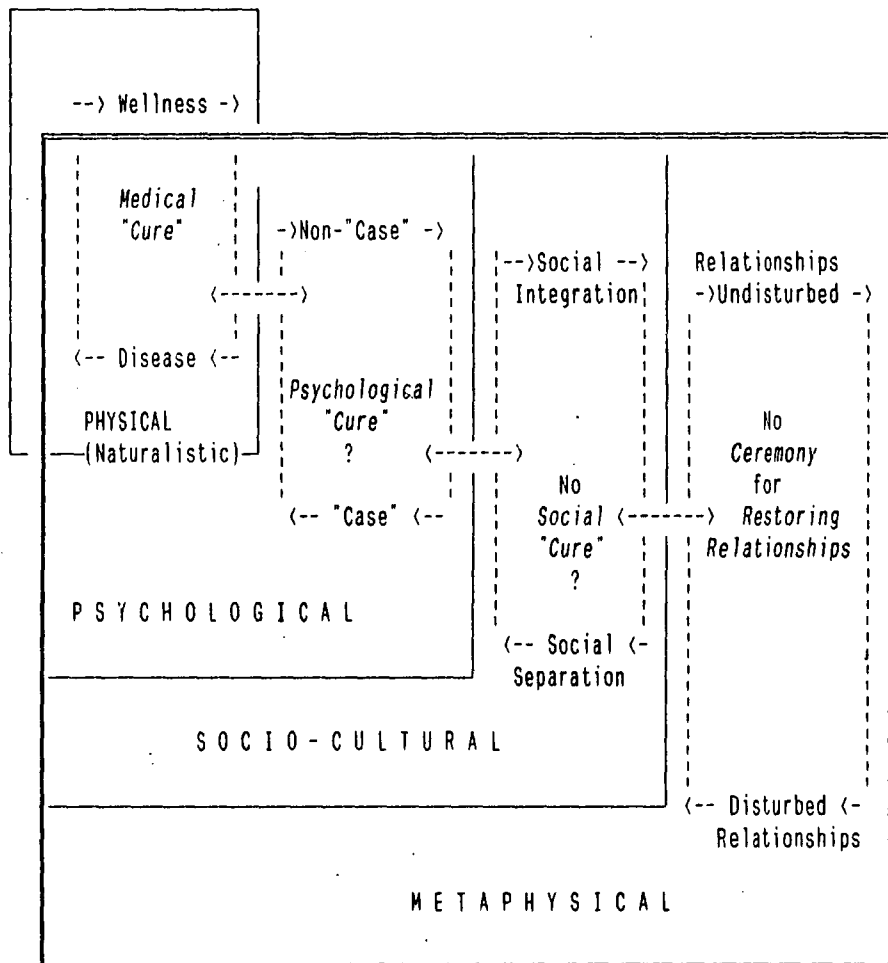


FIGURE 12:5

However here we fly in the face of the nature of scientific medicine which excludes from the picture anything it does not see as fact. Would it make a difference to the notion of "cure" for scientific medical practice to acknowledge that they have only part of the answer to the problem if the problem were to be re-defined in terms of psychological, socio-cultural and metaphysical as well as physical? After all, the present "cure" available to scientific medicine is only part of the answer in relation to the medical problem of leprosy if the physical

"complications" of reactions and nerve damage are recognised as part of the medical definition.

At the moment the health education catch-word "leprosy is curable" is very simple, but it is also very misleading in Nepal. Not only is it misleading, it is inaccurate. To be accurate even in scientific medical terms, it needs to have several qualifications such as: *if* diagnosed early and *if* treated adequately; and *if* reactions are detected early and *if* they are manageable with available therapies. To be realistic in terms of Nepali concepts would require considerable adjustment on the part of health professionals, and to find useful ways forward would require two-way communication between planners and the people of Nepal.

Fourthly, would it be possible to stop what the present education programmes are doing, that is, trying to convince the Nepali public that "leprosy" equals/is "Kushtharog"? Perhaps it would be better to call the "early case" something else, the reason being, as mentioned above, that the person who is diagnosed as ("leprosy" that is "Kushtharog") is liable to be separated if "exposed", even if he is an "early case" with no obvious physical deformity. An accurate statement would be that "early case" leprosy can but need not lead to "late case" leprosy or "Kushtharog" if treatment is adequate and "uncomplicated". Could another label be used which is less socially damaging?

Implications for patients

From the the patients' point of view it is desirable to recognise that the LCP is dealing with these categories of people.

First, there are those who are called "early cases" of leprosy by scientific medicine, who have not "tell-tale" signs which are recognisable as "Kushtharog" in Nepal. These people do not have "Kushtharog" and yet are in danger of being labelled as such. The public health education conducted by the LCP has been partially successful in convincing Nepali people that "leprosy" is "Kushtharog". As they do not have "Kushtharog" in the first place, the message that their condition is curable is more likely

to be believed. There is a need, however, to recognise the socio-cultural reality for these people and to adopt an approach to delivery of treatment which assists with preservation of their social integrity, which becomes their ally in their use of silence and concealment to protect themselves. The present practice of some health workers of using the threat of exposure as a negative "reward" for people who have not come to the clinic on time is not in concert with the needs of these patients and may be entirely counter-productive (see Case Study in Appendix).

Secondly, there is the category of people with leprosy who are those who are called "advanced cases" by scientific medicine and "Kushtharog" in Nepal. Here the message of cure is unlikely to be believed and there is need of another approach. The issue of finding a way back from social isolation to re-integration needs to be confronted.

Implications for the relationship between western and traditional medical practice in Nepal

Some authors have suggested that the faith healers of Nepal could be educated and become part of the scientific medical service in Nepal. For example Shrestha and Ledaird (1980) suggest that they could be incorporated into the national network of service delivery in relation to family planning motivation. They concluded that: "without disruption of traditional beliefs and patterns, Dhami-jhankris can play a major role in accelerating the acceptance of family planning" (1980:124). This suggestion may be based in part on the perception of western scientific medical personnel that the faith healer is their rival in provision of health care in Nepal. Miller (1979:3) disputes this however. His research led him to suggest that "there is room and need for both". He explains his position by saying:

As to the doctor trained in western methods of diagnosis and treatment, though he may at first view the Jhankri as his rival, I believe a closer look would reveal to him that, at least according to the world-view of his village patients, the doctor is treating symptoms while the Jhankri is getting at causes. ... The doctor will certainly realise that a shared world view between patient and physician can be a powerful factor leading to a cure; he should also realise that his modern medical education, based on a secular view of

the world, has deprived him of this advantage which the Jhankri continues to possess.

While the traditional healer in Nepal has a special affinity with the people, and their healing rituals are effective in relieving some problems, they do not work for "early" or "late" leprosy. Several of the patients interviewed gave accounts of using the services of traditional healers in their villages. For two, these rituals were repeated over a long period of time, some years in fact. The result of their recourse to these rituals was to delay their seeking further help for their problems and meant that when they did obtain medical help their leprosy was already "complicated" and "late". One new patient interviewed was very emphatic that after his experience he would never use a faith healer again.

Not everyone is that negative about their traditional healers and many do consult them in the process of seeking help for their problems. However I hesitate to advocate seeking their incorporation into the national network of leprosy control activities. Apart from the issues raised above, I hesitate for a practical reason as well. Miller (1979) found in his study of faith healers that they do not have a network or hierarchy between themselves. Rather they operate individually in their own particular communities. Any effort to implement an education programme for faith healers would therefore be extremely difficult and unlikely to be successful.

Having said that there is an important area in which the faith healers of Nepal may be brought into partnership with the LCP, this is in relation to earlier referral of people with leprosy to scientific medical services. It would be ideal if faith healers trained in diagnosis were to recognise signs of "early case" leprosy and were encouraged to refer people to medical help after they had performed their rituals. Some social reward might be necessary to achieve such outcomes.

As for the other healers, the role of the JANNE (those who know) is an integral and important part of the society of Nepal. They

are consulted routinely for all manner of problems. Given that the traditional wisdom places origin of Kustharog in the metaphysical realm as well as the natural world, the challenge is to find a way with all kinds of healers in Nepal to bring about a return to wholistic wellness for Nepali leprosy patients who have been medically "cured". Some interaction between the 'western' medical healers and the JANNE seems therefore desirable.

For people with leprosy in Nepal and for the Leprosy Control Programme, however, there is no quick and easy answer to improving clinical services, reducing drop-out from clinic, and preventing separation or expulsion from the home and village, although hopefully these findings might have impact on long term planning. There are insights to be had into the socio-cultural meaning behind actions which, if applied creatively in co-operative planning between medical and community leaders, could result in movement towards more acceptable, appropriate and therefore more effective service delivery.

Future research

This thesis touched on but could not deal in depth with some issues which present areas for future exploration and research. For instance:

1. The relationships between visible disability, psychiatric "caseness" and social separation.
2. The particular world of women and minority groups such as Muslims and Christians in relation to leprosy, its meaning and particular socio-cultural conventions which apply.
3. The question of a concept of "cure" for Nepal, finding a way to restore wholeness and health including social restoration.
4. The relative impact of diagnosis, the emotional burden of leprosy and extent of social disruption of life between men and women.

These important questions await further work.

Wider implications

This study of leprosy in Nepal underlines Engel's contention that social conventions form an essential part of the definition of disease in a culture. A disease is defined by the culture in

which it is found. It is important to recognise that this holds true across cultures and for various diseases.

The centrality of the concealment cycle to people in Nepal who have leprosy speaks to the likelihood of similar socio-cultural mechanisms and conventions being crucial in the comprehension and modification of other problems among other peoples in other settings. Such ethnomedical approaches to the structuring of health service, health worker training and public health education which inform about these conventions and meanings, can lead to programmes appropriate and relevant for those they are meant to target even in our own society.

In an international setting for example, these approaches could well apply in relation to the disease of AIDS in western societies. It attracts similar social sanctions and judgements to those attaching to leprosy in Nepal. These insights may also be valuable when planning for and with immigrant populations in Australia and other western cultures. They come from cultures where health and illness are regarded differently. The same applies to aboriginal community health services in Australia.

The wider message of this thesis is that patient compliance, the concept of "cure", and patient careers are related to a range of socio-cultural factors and mechanisms related to medical systems and beliefs, which are embedded in their particular cultural context. Attempts at understanding must draw upon all these factors - medical, psychological, social, cultural, metaphysical - in a non-ethnocentric manner if health programmes and health education are to be better accepted and more effective.

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THE CYCLE OF SEASONS
IN RURAL NEPAL

Rice planted...
(Hyland)



maize tended and...
(Hyland)



soya beans threshed.
(Hyland)

RESEARCH PARTNERS



Srmt Y Gurung
Interview Assistant.
Srmt SM Shrestha
Research Assistant.
(Hyland)



Patient interview
in progress
(Hyland)



Review of tape
recorded interview.
In this case
interpreted from
Tibetan to Nepali.
(Hyland)

LEPROSY PROGRAMME
STAFF WHO TOOK PART
OF THE RESEARCH

The Desirability of Using Sociolinguistic Analysis for Future Research



Leprosy Paramedical
Field Workers from
The Leprosy Mission,
Netherlands Leprosy
Relief Association,
His Majesty's
Government of Nepal
and the
International Nepal
Fellowship with the
author in January
1992.
(The Leprosy
Mission, Kathmandu)



Staff from the
Leprosy Control
Programme and Green
Pastures Leprosy
Hospital at a Health
Education Seminar in
Pokhara, November
1990.
(Hyland)

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APPENDIX A

PATIENT CASE STUDIES ILLUSTRATIVE OF VARIOUS ASPECTS OF THE STUDY

Physical and Social Consequences of Leprosy

Here are details of the experiences of some patients which illustrate the impact of leprosy on their lives. The information given is extracted from interview transcripts, notes of direct observation and clinic records. Interview and question number, with key colloquial words are given in brackets and spoken Nepali in capitals.

TWO CASE STUDIES

CASE STUDY ONE IS MAYA (not her real name) A female new patient. Interview number 2. First met: March 4th. 1990.

Maya is a 33 year old woman, poor and low caste. She lives with her 15 year old daughter. In the village they depend on the goodwill of others as they have no house of their own. They stay on a verandah. Her husband deserted her many years before and lives in the south of Nepal with another wife and family.

A female friend with whom she sometimes worked had told her about Green Pastures Hospital. She is a casual labourer carrying baskets of sand from the river for building contractors. Her friend had said; 'My 'ringworm' (DAAD) was also healed when I went there.' (2/28)

We interviewed her on the day of her first visit. She said she was worried about a single skin patch (DAAD) (2/22) on her ankle which, while she had had it for some time, had increased in size, become 'blue' and raised and cracked over the previous few weeks. She said because of the sand and water.

Physically.

Her clinic card showed she had a single red, raised lesion (plaque), had no disability, skin smear negative.

Her diagnosis was given as Paucibacillary leprosy (PB). She was given one month's supply of the standard medication (PB MDT= 6 months) and told to come back.

Her explanation.

Maya insisted what she had was (DAAD) ringworm (2/50) and expected it to get better with the application of ointment and medicines for one month. She spoke of having left it in god's (BHAGWAN) hands.

Maya is Five Months Late for her Next Clinic Visit. Second meeting. September 4th.

She returned to the clinic not one month but six months later having missed five months of medication. When she came the OPD staff notified us and we were able to interview her and then unobtrusively observe and overhear her encounter with the clinic staff. She had already been received by the OPD clerk who had extracted the customary fine for a patient being late. She paid Rs7/-.

Her Reason for Being Late?

Soon after her last visit to the clinic she had been summoned to her maternal home (MAITE), one full day's bus journey away. As custom requires, she had been accompanied there (and back) by a friend or family member. She did not tell them about her problem or that she was on medication, nor of her clinic appointment. She said she was unwell with diarrhoea and vomiting for two months. Then her father was sick so she stayed on. Eventually

she was escorted back to Pokhra two days before she came back to the clinic. She told us; "I wanted to come but they did not bring me.". "They (the clinic staff) told me to come, they told me not to stop the medicine, they told me I have to take it for six months. I have lost my card, I am afraid they will be angry. I could not come until now."

Since her last visit Maya had experienced tingling and shooting pains in her leg. Since her last visit she had apparently been able to obtain a small piece of land and build a hut on it, where her husband had given her permission to build, next to a landslide.

Her encounter with the Health Worker.

He was a high caste Nepali male, somewhat younger than the patient, trained in general health and leprosy treatment with about ten years experience in the leprosy clinic.

The Nepali Research Assistant made the following record of the encounter.

HW: You are five months late! We can't give medicine to such a person as you!

P: Please give it. I had gone to my maternal home. Because I was sick I could not come.

HW: If you were sick you should have come here. Why have you stayed at home?

P: I wanted to come but they did not bring me. That is why I have come now, immediately upon my return.

The HW became more angry and said she was deceiving him. He spoke of late letters, hinting that if a letter was sent to her the village people would find out she had leprosy. He asked her what she would do if her hands and feet got like this, gesturing with hands clawed. He went on being angry with her for a long time. But she would not stop saying; "I will take it". Only after the patient began crying did the HW begin speaking more softly and kindly.

He did not ask the patient anything about how she was (physically). He did not explain anything about what is likely to happen if and when the medicine is stopped. He only threatened late letters. The HW did not listen to anything the patient had to say. He gave her a form to get a blood test, then she looked very happy.

The foreign Researcher noted the following additional points about the encounter.

HW: You must come. You did not come. You said you would come monthly. Why did you not come? You have not taken the medicine. If you want to get better you would come, you would take the medicine.

P: I will not leave it again.

HW: You will leave it.

P: I will not. I was far away, I could not come, I did not have the bus fare.

HW: We do not give medicine from here to this kind of person.

P: I am in the wrong.

HW: You are not a child. This is a hospital. You can't come here when you please, you have to obey us (do as we say).

HW: You will leave it again.

P: I will not.

For part of this encounter the patient and the health worker were both speaking loudly at the same time. She apologises. He calls her a liar;

HW "Why did you not say that last time?"

P: It had not yet come up then.

HW: Now you can start medicine again. Can you come?

P: Yes.

HW: You want a good body, if your feet are spoiled your future is spoiled. Go and have a blood test.

P: My life is good. I made a mistake. I am bringing up a daughter.

HW: Go and have a blood test.

She came back.

Comment. This foreign Researcher noted the following at the end of the above record. *"I think we witnessed the 'sending away' of a patient today."* My Western interpretation of this encounter was wrong. She did return. She attended regularly for the following five months and completed her treatment with no resultant disability. It seemed that she had genuinely been prevented from coming back after her first visit. She showed strong resolve to come as required. Each time, in order to do so, she would have to forgo one full day's wages. That is a high cost for a casual labourer with a dependent daughter and living from hand to mouth. I wonder however, if her physical problem had not given her some more trouble (tingling and shooting pains) after her first visit, whether she might not have returned. Maya was not convinced she had leprosy. She had DAAD.

CASE STUDY TWO. A family with leprosy: two new male patients. Interviews 4, 5 and 9. First meeting March 9th. 1990.

We were informed by the OPD staff that two new patients had arrived. They both agreed to talk to us and were interviewed individually. What unfolded was a fascinating story of leprosy in a family and how they had dealt with it. Because of this unique opportunity I have made this a longer case study. We gained information from the two new patients themselves and from hospital records. The LCP staff member also recalled his dealings with them. They were observed repeatedly at the hospital. Finally a visit was made to the village. Both men were interviewed in Ram's home. Thus it was possible to cross check and verify information and gain a more complete and reliable picture of their illness career than was possible from other interviewees.

Ram (not his real name: Interview 4) is a 38 year old high caste man, one of three brothers. He has recently separated his home from the family home (normal practice). He is married and has three sons and one daughter. He works as a farm labourer at a local agricultural development project. He has some land which he also farms.

Lal (not his real name: Interview 5.) The other new patient turned out to be Ram's father. He is 66 years old, has only one of his three sons at home. His four daughters are married and live at the homes of in-laws, away from their maternal home. He has land and lives off it. At times he acts as a Brahmin Priest for his local community.

A family member with leprosy dies.

Both men told the story of another member of the family who had died at Green Pastures three weeks before our interviews. The middle brother (son) had had leprosy had been on treatment for 46 months. He had become ill and died in hospital. Both men were convinced that he had died of leprosy. From his hospital record it was found that he died of acute anaemia and heart failure, having had an abnormal blood condition which could have been leukaemia. He had also had an amoebic liver abscess aspirated

recently. His leprosy was improving slowly with the positive smear (initially 5+) reduced to 2+ on his last test. He had worked in India for some years where he had become ill. He, and the company for whom he worked, sent word to his family. The father sent the eldest son to India to find and bring his brother home. This he did after one unsuccessful trip. Once home he stayed in the village for two further years, with no outside treatment. Eventually he went to Green Pastures Hospital, having been urged many times by a neighbour who is a staff member of the LCP.

Physically

He was found to have advanced Lepromatous leprosy, with heavy skin infiltration, nodules and 8 enlarged nerves and swollen feet. He had already had at least one episode of ENL. He had no disabilities and a split skin smear reading of 5+ with a nasal reading of 2+ positive, indicating he had highly infectious leprosy. He had had the symptoms for four years prior to coming to the hospital. Routine MB MDT was continued regularly, he came to the clinic every second month for the next four years. Each visit necessitated three days' lost income. The progressive improvement of his leprosy was however not paralleled by his general well-being. He reported aches and pains, headaches, had scabies, fever and chest pain at various times. As mentioned above he eventually died at age 36 after eight days in hospital.

His Brother and Father With Leprosy.

Three weeks later his brother and father arrived at the hospital, both with advanced leprosy. From the story it seems very likely that they both caught leprosy from the man with advanced infectious leprosy who sat at home ill without biomedical treatment for two years.

Ram's Story.

Now to pick up the story of Ram, brother of the dead man.

Physically.

He was diagnosed as having Borderline Lepromatous leprosy, with a smear 4+, no disability, but 7 enlarged nerves. He had many red plaques, particularly on his face. He commenced and continued regularly on routine MB MDT.

Etiology.

His notion of causation was clear, he stated he caught leprosy from his brother. His response to the diagnosis was of interest.

Response to Diagnosis.

In the second interview he used many very strong negative expressions and seemed to be depressed. For example, referring to his deceased brother, he said; "He destroyed (BABADI) all the members of the family". (9/26) "Now he has affected (BARBAAD BANAAYO) all the members of the family. (9/37) "He ruined (BABAAL BANAAYO) all the people." (9/43) "It is very frightening (DAR SAAHRAI BHADDAA BHAYO)." (9/56) "Of course I am anxious. All the members of the family are very anxious (EKDAM BHADDAA BHAYO) about it." (9/61) Q. "Have your children got this disease?" A. "They haven't got this disease. If they get like this ... everyone will be finished. (KHATTAM) (9/62) "This disease is going to finish me. (KHATTAM GARNA LAGAYO) If I had known about this disease I would never have gone there." (to India) (9/64)

Psychological.

At this second meeting the Self-Reporting Questionnaire was administered. He scored only 6 (negative) but he said he had been depressed before.

Consequences of sustaining treatment.

On subsequent meetings his outlook seemed much brighter. He was visibly improving and the complications he experienced at first

did not recur. He seemed to be coming to terms with his treatment. For example, on one occasion he volunteered his own way of coping with the 'black' medicine which was said to be 'hot'. 'Take it with milk and it is not hot.' (The pharmaceutical advice about taking this medicine, which is fat-soluble, suggests it be taken with fat/oil based food or drink. Milk, with its cream (fat) content, is ideal!)

Lal's story.

Physically.

He was found to have Borderline leprosy, with mild reversal reaction, lagophthalmos, parasthesia and anesthesia of both feet and hands. The smear result was 1+ positive and disability grade WHO 2, extent 5.

His physical symptoms had been building up for at least 16 months. First one of his eyes began burning and tearing. (A slight Lagophthalmos where the tears are no longer drained away by the tear duct because its opening is not against the eyeball because the lower lid is slack.) After this he noticed one of his toes was numb (NINDAYO - gone to sleep) and then the sole of the foot also 'went to sleep'. He noticed this first when working in the paddy fields planting rice, with his feet in water all the time. It did not seem numb after that for some time but the numbness returned. One of his hands also became numb after that, then the other hand as well. His hand felt as if it had been burned by nettles (SISNALE POLEKO). Following that swellings or nodules (PHOKA) appeared and he experienced shooting pains in his forearm, like hitting his 'funny-bone'. At one stage his whole body itched (CHILYO).

Symptoms Interfere With Normal Life Activities.

From his experience he came to believe that his condition was steadily worsening. (5/100) He said; 'I think this disease will kill me. (MARNU PARCHA).

Apart from these physical aspects of his problem, which caused discomfort and disquiet, he experienced interference with his normal life activities. "I have to walk." (5/16) "My leg used to be strong." (5/16). "I can't walk (TEKNA NAHUNU), (5/46) 'I can't feel my shoes, they fall off." (5/31) "I am not able to eat (feed myself with my hands)," (KHANA NAHUNU), (5/46) "I can't grasp and hold vessels, I can't feel, I drop them." (BHADO SAMAYERA PANI KERE NAPAUNE, PHUTKANE CHODIDINE) (5/46) His eyes did not see well either. For him this is a *big* problem (THULO SAMASYA).

Etiology.

When asked the reason for or the meaning of his problem he spoke of "This disease (ROG) has entered (me)." (PRABESH GARYA) (5/18) He introduced the word ROG which means a *serious* disease. He spoke of having trouble (DUKHA), "What has happened, now in my old age (time of dying) I have such a disease passed into me. (JHAN ROGLE PRABESH GARYO) (5/18) "What sin have I committed (PAAP) in a past life? Here I am old, my son should have done my funeral rites (KIRYA) for me - I have to do them for him - what fate (DASHA) is this? (5/51). "O god, (BHAGVAN) this disease entered me at my time of dying, don't give me trouble (DUKHA) I will give you a lamb." (sacrifice).

Psychological.

For the father of the dead leprosy patient, being diagnosed as having leprosy is a major life crisis.

The results of SRQ were positive (14/20) for Lal. He was obviously depressed.

In the whole conversation he, like many others, avoided giving a name to his problem. Q. 'What do you think this disease is?' (5/55) A. 'Whatever is written, I have to bear it.' Or, it is a matter of not finding

happiness if what is written is not borne. Q. "How did you get this?"
A. "I don't know, if I knew I would be a god!" (5/56)

Help Seeking.

More than once he had gone to an astrologer (HERIYO) (to have it 'seen'). He said he was going to fulfill a vow (BHAKAL) (promise to the gods for fulfilment of desire), but he had been unable to do this for various reasons, some of them to do with it being inappropriate, inauspicious to do the religious ceremony (PUJA) at the time because, for instance, a member of his family had given birth (SUTKERI BHAYO). His son's death meant he had to wait 12 months before he could fulfil the promise. This worried him. However when pressed on the subject he confessed doubt that the (BHAKAL) would be sufficient. Q. "Is this your confidence, that the worship (PUJAS) will fulfil your desire?" He did not answer. Q. "You made a vow there - you have come here - how did you come?" A. "I came here thinking - it will be alright (get better) but not just with the vow (BHAKAL) (5/67) 'Perhaps it is not (to be better) by a vow.' (5/73) He was also concerned that a god of a local piece of land may be causing trouble. Later in the interview the question of the origin of his problem was again brought up. He then speculated about his forebears, hinting perhaps at an idea of heredity. - "No such disease has come out in my father or grandfather's time. This disease was not in my lineage, clan... My son's mother-in-law has said that he would die after working for the development project. (BIKAAS)... It is not by fate (DASHA), it is not by spreading (infection) (SARERA), I don't know how I got this disease." (5/110). The help-seeking he admitted to was mainly related to his speculations about metaphysical origins for his problem. First he seemed to have sought simple physical, village remedies or well known medicines to relieve his symptoms. For his body itch he scratched, and as it seemed like scabies (LUTO) washed his body with water infused with herbal leaves (PAATI), the usual village remedy. He went to a Medical Store in Pokhara to get ointment for his eye problem. He denied calling the LAMA JHAKRI or Priest (PUJAHARI). He denied doing (GAREKO) anything but admitted going somewhere (GAYEKO) (5/61.) Only after being asked about going did the matter of the vow come up. Going to the astrologer means that he 'caused his problem or situation to be looked at' (HERAUNU) by the 'one who sees' (HERNE MANCHE). Not having been able to fulfil his vow (BHAKAL) seemed to worry him. He gave his opinion about hills (LEKH) people seeking help for physical problems. They "only seek help (SODH-KHOJ) (ask-seek) when at last they cannot work at all. (BALLA KHOI GARNE). (5/84) He had been advised to go to Pokhara by village friends, by the local man who worked in the LCP, he knew of the hospital from his dead son's visits and his oldest son going there. He said his wife and family sent him on this his first visit. "You have to look after your eyes."

The expectations he had of the treatment at Green Pastures is of particular interest. A number of interviewees' expectations are for relief of their symptoms. The health workers, however, are interested in seeing the smear result reduced to negative. Q. "What kind of treatment (UPACHAR) do you expect?" A. "Perhaps they will do treatment by giving injection (SUI) (5/79 & 5/97), by giving medicine (DABAI) even XRay perhaps. My eye also will perhaps get better (SANCHO), with this hope I have come." (5/97) Q. "Your problem, is it serious or what?" A. "It is serious, it is progressively getting worse. (5/100) Q. "How long will it take to get better?" A. "Not immediately, after a little while it will be better." (JATI HUNCHA). (5/101) Q. "Are you hoping to do anything after this is better?" (NIKO BHYE PACHI) or does it seem that it will become a more difficult problem?" A. "This is my thought, if I could work, if I could cut grass, if I could do farming, if I could keep (look after) domestic animals - it seems to me I would not die soon. (5/103)

He seems to expect to regain the lost function and faculty of his body. Then he would be cured. However, the Health Worker looks for a progressive reduction of the smear count. If and when this occurs, he will be cured.

Help-seeking for the Deceased member of the family was detailed by his brother during our second interview. In the village the following traditional measures were taken. The astrologer was consulted (HERAECH), the LAMA-JHAKRI was called, and everything was done according to his instructions. (LAMA-JHAKRILE BHANE ANUSAR GARIYO SAB), which meant the sacrifice of a sheep and chickens and entailed the spending of between RS2 and 3,000/-. They also blew (PHUKPHAAK GARYO). However he got much worse (JHAN SAHRO BHAYO). Before he had been brought back from India to his home in Nepal he had spent a lot of money on sacrificing chickens, and had also been in hospital. It was actually from the hospital that his brother fetched him. When asked if the Indian hospital had given a name to the condition they said no.

More information from a neighbour, a staff member of the LCP. He had advised the family to take the other brother to Green Pastures more than a year before he actually went. The wife of the sick man apparently cried and begged her father-in-law, Lal, to send her husband for treatment. All the time the old man resisted her pleading as he did the advice of the LCP worker. It was the LCP worker himself who eventually took him to the hospital and gave him a letter to the clinic staff. Not only did Lal resist when advised to send his son to the hospital, he also resisted when advised by the same LCP worker neighbour to go himself. The LCP worker had advised the old man to go to the hospital more than one year before he actually turned up after his son's death. At that time he had had no deformity, but had had at least one episode of ENL.

Consequences for Ram and Lal of their continuing treatment from Green Pastures hospital. It was possible to meet these men occasionally over the following months until the end of the main data-gathering period, to review their case notes at the end of 1990 and again at the end of 1991. It was also possible to meet them again in 1991 and, assisted by the LCP worker, make a brief visit to their village.

Physical progress

Lal.

On his first visit this patient was found to have mild Reversal Reaction. Three months after commencing treatment he had an episode of severe Reversal Reaction. The initial episode was treated with Chloroquin and Aspirin and the second with a course of Predniselone. He was admitted to hospital after this for an operation (Tarsporaphy) to stop his eyelid sagging. This was not a total success. His eye continued to tear. The disability grade initially was WHO 2, extent 5. After 22 regular monthly doses of MB MDT it was WHO 2, extent 2, which means that he has recovered the facility and function in three of the five areas initially affected. At the end of 1991 he was continuing regularly on his treatment and his smear result had reduced to negative. He will be due for release from control after 24 doses and two negative smears. A good result clinically.

Ram.

On his first visit he had red raised skin patches (plaques) but no other signs of Reversal Reaction, however, two months after commencing MB MDT he had an acute episode which was treated for

three months successfully with Chloroquin and Aspirin. He did not need to be admitted to hospital. He continued regularly on his treatment, having taken 22 regular monthly doses, with no problems. By the end of 1991 his smear was reduced to 1+ and he continued to have no disabilities. His treatment will continue until his smear is negative. His also is a good result clinically so far.

Social Consequences of Leprosy?

Even though this misfortune came to the family it does not seem to have had lasting social consequences.

Lal.

On one of our meetings we had asked Lal what would happen if people in his village came to know he had leprosy, because he was **keeping it secret**. He replied that they would no longer call him to officiate as a Brahmin Priest at their religious ceremonies (**PUJAS**). It seemed that he regarded being known as a leprosy patient as disqualifying him from this role. In 1991 I enquired of the LCP worker whether the village people knew of his condition. They did not talk about it. In other words they were not making an issue of it by bringing it into the open. We also asked the patient if others knew of his condition. He said no and they were still calling him for **PUJAS**.

It seems that his status in the village is not affected by his condition even though people are aware of it. Perhaps this bears out the comments of community members who say that the social consequences of having leprosy depend on the person's previous status and reputation in their community. Leprosy at times seems to be used as the reason for giving a person a hard time. On those occasions the person in question had previously been judged as undesirable in some way. A great deal more could be looked into in relation to this stigmatizing of leprosy patients that is beyond the scope of this study.

Ram.

For his son, Ram, the story was also satisfactory. Not long before we met him again in 1991 he had built a separate house for his wife and family. We visited this house. It is next to a new road which, incidently, had 'eaten' a section of his farm land. No compensation is paid to those who lost farm land, only to those who had lost their house and had to build another. He continued work at the development project, from which he took leave, and had forgone wages, each clinic visit to Pokhra. He had probably lost 13 days wages during his treatment up to then. He preferred to go to Pokhra for the treatment rather than getting it from a Health Post near to his home. He also was **keeping his condition secret** (using the device of silence and concealment expanded in chapter twelve) and was anxious about what would happen if people knew. He seems to have been more successful than his father, because according to the LCP worker, people do not know about him. This placed a constraint on my visit to his house as I did not want to jeopardise his social well-being. To the curious hotel keeper where I stayed I was involved in health work.

The follow up of defaulting patients from Green Pastures was mentioned above. Here their situations are presented and discussed in more detail.

APPENDIX B
SUMMARY REPORT OF FOLLOW-UP STUDY OF TEN DEFAULTING PATIENTS FROM
GREEN PASTURES HOSPITAL

Limitations on the study.

Ideally it would have been good to follow-up all the defaulting, or Out of Control (OC) Cohort patients. Out of Control means that more than 12 months had passed since the patient had been to the clinic for medicine. However limited time and finances confined the study to one month's work for two persons.

Selection of OC Patients to visit at home.

Of the GP Cohort Patients who were listed as defaulters ten were selected to follow up by home visit. Those patients living in nearby districts accessible by road and within one day's walk of the road were chosen.

The Research Assistant chosen was a trained and experienced Leprosy paramedical worker who had been working in the Social and Economic Services Department (SES) of Green Pastures for some time. He is a high caste and well educated man. He was accompanied by one of the junior SES staff to assist and be his 'friend for the road'. The SES Head was most helpful in this selection and in making his staff available for the study.

Interviewer Training:

The Research Assistant was instructed in the interview technique, given the topic list and practiced on some patients. He listened to some of the taped interviews and the results were discussed. He proved very good at the technique and grasped the method and purpose of the study very readily.

His instructions included:

1. Go to the patients' homes and if possible meet and converse with them in such a way that their social situation is not jeopardised.
2. Tape an interview using the topic list and reflective style.
3. Do a simple physical examination and complete the standard chart for skin, hands, feet and eyes so that the activity of the disease and the deformity grade can be ascertained.
4. Complete the 20 question SRQ for ascertaining indications of psychiatric 'caseness'.
5. Keep a field diary from which to write a brief report of each visit.

The study took place between 047/6/26 and 047/7/23 (Oct 12 - Nov 9 1990)

This report is compiled using the different material available about each patient. These included:

- a) The translation of the transcribed interview tape (and the Nepali transcription)
- b) Notes on conversations with family or neighbours made by the research assistant. (in Nepali)
- c) His report. (in Nepali)
- d) Completed SRQ results.
- e) Physical examination charts and
- f) Hospital Out-patients card information as copied onto the Cohort Form I.

The research assistant and his companion travelled by bus and foot to each of the village homes of the patients. He succeeded in meeting six of the ten patients. He met family or neighbours of the others. Five patients agreed to a tape recorded interview, one 'ran away' after an angry outburst.

An unscheduled return to Pokhara was necessary after the 7th visit because the tape recorder was "lost". (See notes on Interview No 39). The Research Assistant took his own tape recorder to do the last interviews but, as it was old, the quality of the recording was poor. A transcript was not possible so a summary was done in consultation with the Research Assistant. (Interview No. 41)

Loose Translation of the Summary Report of the Research Assistant which he titled "Facts from the Field".

1. It was possible to meet only six of the ten patients at their homes. They were Sri. Pariyar, Ali, Sunar, Sharma, Magar and Damai.

2. It was found that among all the patients six having spent more than 15-20 years in India in a variety of occupations were not living at home. These were.

- a) Sri Pant (non-permanent work)
- b) Sri Pariyar (Army)
- c) Sri Magar (non-permanent work)
- d) Sri Sunar (factory)
- e) Sri Sharma (non-permanent work)
- f) Sri Magar (factory)

3. It is understood that some patients have gone to India since the disease struck. These are

- a) Sri Magar: when he was small he was in India but having come back to Nepal he had not gone to India again. Now after about 45 years he has returned to India.
- b) Sri Jaisi: he had never been to India, but when he got the disease he went to India both to get treatment and to work to earn his living.

4. But Sri Pariyar is one patient who left his work in India early. He says that he thinks treatment is easier in Nepal. Among the patients met he appears to be the most anxious and he is the only one found to have 'Reaction'. (Reaction; physical symptoms of immunological instability such as fever, crops of painful red lumps, joint pains, swelling and so on.) He is the only one of the ten who was found to be continuing to take medication from a second place.

5. Some patients after returning from India found that they could not get on with their families, and their families were not caring for them either. These are:

- a) Sri Sharma
- b) Sri Pant

Neither of these patients' families was found to be stable (permanent). According to the explanation given after questioning it was understood that Sri M Pant has 'gone mad'. Before the disease was recognized in either patient it seems there were family quarrels about property.

6. Sri Ali, Sri Sharma and Sri Magar all seem to think that they will probably get better now without taking medications.

7. Sri Damai was the patient who was not ready to be interviewed and who fled. It was found that after this patient got the disease and his family found out they have not given him advice to take medicine. One of the family members was angry when it was said that Sri Damai is a leprosy patient. (KUSTHA ROGI).

8. All the interviewed patients and their families have found the black (discolouration of the) skin resulting from the medication, and their neighbours continually asking about it, to be a problem (difficulty).

9. None of the interviewed patients could say it was definitely leprosy (KUSTHA ROG).

10. Only one patient, Sri Sunar, explained that the reason he could not come for medicine was economic and physical (bodily) weakness.

11. Two patients, Sri Pariyar and Sri Sharma, were found to have left their villages and to be working 'outside'.

There follow detailed notes on each patient and the circumstances of the visit to their home or village, and of the interview.

1. *Sri Pant*

The patient's older brother told that the patient had left the home about three years before. Upon asking a neighbour on the path the answer was given that the patient is mad and does not stay at home and where he is now is not known.

It was understood from the patient's older brother that the patient's wife and one of his daughters had gone to live in an ASHRAM in a nearby town. But it was found that the patient had left his wife and daughter and become a JOGI and gone off begging.

Some of Sri Pant's family and community had come to know about his disease. It was discovered that people found out that he has leprosy when a letter came from Green Pastures Hospital, and they began asking about it. But it appears that no-one made an objection or obstacle of this. It is understood that Sri Pant, some time before, had exhibited unusual behaviour such as shouting, rage, breaking off and planting branches of any tree any time, and watering plants during the monsoon season. It is understood that the patient is completely insane.

There do not seem to be problems from the community. In that same village it was discovered that there are two leprosy patients taking regular treatment and no one has objected to that. It was reported that when patients began wearing shoes the villagers started talking about it. Sri Pant however did not explain and the villagers were not able to find out anything. It was found that he is said to have run away to India when he was small and only returned to his home after many years away.

2. *Sri Ali* Interview 38

It was found that apart from his wife no one among his family or neighbours knows about his condition. The patient told that after taking the medicine he was better and then stopped taking the medicine. As well the patient seems to think that because he is tending towards (old) age he will not be able to be very 'spoiled' (deformed) anyway. He thinks that he does not want anyone in his village to know about his condition. After he began taking medicine his skin became (discoloured) black and then his neighbours began asking a lot of questions. He also said that his hands and feet began to tingle more.

It is understood that he left off taking the medicine after he became somewhat better and because of his skin becoming black. As well as this the patient did not seem happy after having to pay a fine at the Green Pastures Hospital. But it can not be said that this is the only reason for him stopping the medicine. Because he did not like the injustice of Green Pastures he could not take their medicine. A few days before our visit the previous Health Post worker had returned to the village and given him advice to take medicine. He had written a prescription on which the name LAMPRENE was not seen. In my opinion one can learn from this that the patient does not like the black skin discolouration.

The patient gave his help with the interview without hesitation. When asked question 17 (SRQ) he said this seems to be mine! In the Muslim religion it seems that those who have been to Mecca and Madina on pilgrimage and those who die on the road (the way) are regarded as holy. After returning it is necessary to remain separated from commerce and for this reason he thinks it would be OK if he died now.

He has no financial problem. It takes one day to reach Pokhra. During the monsoon the river can cause a barrier. There is a Health Post in his village.

3. *Sri Magar*

Because the patient is continuing his service in India it was not possible to meet him. According to his wife his service is not permanent. His present address (in India) was found from a letter he had written.

It is understood that his family and neighbours had no idea of his disease. His wife had sent on to India the letter sent from Green Pastures Hospital, Pokhra. It was found that his wife did not know nor had her husband explained about this disease to anyone.

The patient's physical condition is not changed (the same as usual) so she said. It was understood from his neighbours and family that he had gone to earn wages in India because of economic difficulties at home.

From the wife it was learned that up to that time none of the neighbours had talked about his disease at all.

The patient's house is at the edge of the village. The villagers are all Magars. To go from the village to Pokhra would take two

days. Even though the river is not a problem because of the suspension bridge the road is steep up and down. The village is about one full day's walk from the motor road (from where a bus can be obtained to Pokhra).

There is a Health Post in the village itself, one hour's walk from the house. It was found out from his fellow villagers who had gone with him to India that Sri Magar is well and not taking any medicine whatever. It was learned from one Sri D. Magar (the village leader) that some years before Sri Magar's wife and daughter had gone to Green Pastures Hospital and asked for two month's medicine for him but were not given it. Because of this he had been very angry when they had told him that they had come back empty handed, but there had been no talk of his disease. It seems that this village leader did not know that Green Pastures Hospital gives leprosy treatment.

A letter from Green Pastures Hospital had come to the village once but no one found out from that. It seems that no one knows about Green Pastures Hospital in the village. It seems that the patient really has gone to India for salary earning, and that his usual habit when he returns to his home is to stay a week or so then go off again.

It is understood from his neighbours that Sri Magar was referred to Green Pastures from the local Health Post. His neighbours said that the patient's financial condition is very weak and that is why he has gone to earn in India. They said that Sri Magar had lived in India (Asam) since he was small.

4. *Sri Pariyar.* Interview 37.

The patient was met in a town beside the motor road. He is staying there and engaged in sewing for a living. He said that while he was staying in the village his only son had been stung by wild bees and had died, therefore he had no mind to stay in the village any longer. Even though the patient said that no one in his village knows about his disease it was found that some there did know. In particular two people know, who are both leprosy patients (KUSTHA ROGI) and of his own caste and relatives.

The patient told that his wife and daughter know about his disease. It was found that the patient is taking medicine from this town. He has no nerve damage. He was found to be in Reversal Reaction. The patient spoke of both his anxiety and of fear about fever coming, his body swelling, his skin going red. No one in the town where he is knows about his disease. No economic or social problems were visible, but the patient seemed very anxious. There is fear of the river rising during the monsoon season. The Health Post was far from his home and it is quicker and easier (to obtain treatment) in the town.

5. *Sri Damai.*

Because this patient upon meeting us immediately had a fright and fled, we were unable to find out anything from him. The matters found out from his father and from a neighbour, Sri Gurung are given below.

According to his father Sri K. Damai:

Because their neighbours were angry with the Kulbi and Damais they had paid the Health Post worker to feed Leprosy (KUSTHAROGI) medicine to his son. His son does not have Leprosy. If he had it he should have been 'spoiled' (BIGRI SAKKO HUNU PARCHA) by now. "I felt like accusing those who said that my son is a leper (KORI) but I did nothing. The statement that Pokhra doctors, having given my son a 'violent blast', have given him medicine is, I discover, the KUBIR (the crossing of a crocodile-infested river) of the Damais. My son has taken to drinking RAKSHI (alcohol) in excess too." Even though he was not ready to give a recorded interview we tried to get him to talk to us 'off the record'. In the end, after explaining to him, we advised him to bring his son to Pokhra but I do not believe he will come.

According to Sri Gurung:

The patient drinks a lot of RAKSHI. No matter how many wives he takes he cannot stay with them more than a month. Sri Damai cannot leave off being attracted to women at all. One time the village leader said to him; "You have got leprosy (KUSTHA ROG), don't live together (with other people) in your home and village." At this the patient said nothing but his father was hurt. He is OK when he does not drink but when he drinks all the money he has made is finished.

Now the patient has gone to a neighbouring village and stays there (two hours walk away). He has no house or land of his own. He receives the grain from some fields because the neighbours have left off growing rice there. Apart from this he fashions fibre mats, baskets, rice sifters and so on. From these he makes a good living. It is nothing to the patient that his family has nothing to eat or wear.

According to the patient himself:

The patient, having refused to do a recorded interview fled. While fleeing he shouted; "I am not a Leper (KORI), there is nothing the matter with me.!" But even from a distance the patient's left hand looked wasted (weak). Because he had long pants nothing else was seen but he seemed to run with ease.

According to the Health Post Worker:

The patient has not had enough health education. We found that because the neighbours still have 'old ideas' it was not possible to explain and persuade the patients about leprosy treatment. We asked Sri Guring to explain to him.

To come to Pokhra from his village takes two days. The road is a very difficult steep one. In the monsoon there is danger from the river. The Health Post is in the village itself.

6. Sri Magar Interview 39

Interviewer Report

His family knows about his disease but no one in his community knows. He was found living together with his family, their economic condition was good. To go to Pokhra from his home takes one day. There did not seem to be any difficulties on the road, it is an easy road.

They had not let anyone know that he was taking medicine from Green Pastures, and when the time came for him to take medicine

for the last time (the end of the "Dexo" course) he thought occurred that perhaps he would be OK without taking the medicine. After the medicine had made him black his neighbours began to ask but the patient did not explain about the disease. Some time before receiving treatment there was KUL PUJA in his home and after doing it he found rest from his disease.

He said this before but when taping his story he would not admit this. He and his family seem satisfied (happy) now that his disease is better. During the interview programme the patient gave excessively brief 'yes' and 'no' answers. It seemed that the patient was afraid of us.

It is possible that he had no community difficulties because of the proximity of Malunga and the presence of other leprosy patients in his village. He came to know that he had this disease after returning from working a long time in India. He could not go (for treatment) the last time he was called because of seasonal field (farm) work.

After this was finished he was afraid to go because he would probably be given GALI (be 'told off') for being late. It was not possible to learn anything else from his wife or others.

Remarks:

This patient was among the six (often followed) who were living with their families and could be met and talked to. He was among another six who had returned after serving over 15 years in India. Among the patients met he is the only one who had had (Reversal) Reaction. After the interview he (and two others) seemed to be thinking about taking medicine. He and his family, like all the patients interviewed, found the black discolouration of the skin to be a problem. He, like all the interviewees, could not admit that he was a KUSTHA ROGI (Leprosy patient).

7. Sri Sunar Interview 41

The patient and his wife were met at their village home. Both physical and economic problems were obvious. The patient appears extremely weak physically. It is difficult for him to walk properly. We heard from both the neighbours and the patient himself that he falls even when he tries to walk with the aid of sticks. He had an injury on his arm from such a fall several days before.

The patient also told of added troubles, he has a bad, persistent cough. Apart from his wife no one else knows about his disease. The patient explained that because of his extreme physical weakness and not having the money he had not been able to go to Green Pastures Hospital. Now he talks of coming to Green Pastures.

The patient had spent a long time living in India. There is no person in his home to help him. It seems that his two sons had gone to India, the elder had died in an accident, the younger one, although earning money there, does not help his parents at all.

To go to Pokhra from the patient's house would take a healthy person one day and it was unlikely he could manage it. In the monsoon season there is extreme danger from the river. Even though both his legs are very weak it did not appear that he has foot drop.

8. Sri Sharma

It is understood that Sri Sharma is in India. The following information was obtained from his younger brother and his mother.

According to his younger brother:

He does not know what disease his brother has got. He knows he is in India, but where and what he is doing he does not know. He has already sold his land (inherited) and gone. He has heard that his brother has a wife and son but he has never seen them.

His brother ran away to India when he was young and came back after many years. He drank heavily and his chest was weak. He did not stay at home much, he used to wander round other (outside) places a lot.

He only heard from his neighbours that his brother obtained chest medicine from Pokhra and Syanja. 'I did not ask him about his disease and he did not tell me either.' said the younger brother. It seemed to the Interviewers that this brother was hiding (concealing) information about his brother, especially about his medicine.

According to the mother:

The patient had left home when he was about 14-15 years old and had only come home again about 21 years later. He was so changed he was not recognized at first. When he came home he began asking for his inheritance. We understood from his mother that he drank and had a lot of fights (arguments). He did not stay at home much, but used to go from village to village. About 3-4 years after coming home he went back to India. She said that she does not know where he is or what he is doing now. She does not know what disease her son has. When he was leaving for India he got his father and mother to blow (on him) because he said "What if I die." (I am not sure of this translation. JH) It is understood that there had been a fight about inheritance (property).

His mother told us that Sri Sharma had gone to Pokhra with his middle brother to get medicine. He said he went to the Gandaki Hospital and came back home after getting medicine from there.

From our enquiries it seems that Sri Sharma did not get on well with his family. There seems to be no effort to find him. We found that his disease is not known about in the village community, but even though his family all say they do not know, it is likely that they do know because a letter came once from Green Pastures Hospital, according to one neighbour. However this cannot be said for certain.

To go to Pokhra from the patient's home is an easy day's journey. There are many buses and there is no problem crossing rivers.

It does not appear that Sri Sharma has permanent work and wages in India. One neighbour told of meeting him in Delhi and of his talking about going home, but saying that there was nothing of his left there now and what would he eat.

The brothers are separated (means that the extended household has broken up and the land been divided among the brothers, each then could form his own household). In this case there is one house and one brother is saving to build a house. Sri Sharma was not able to build one. He sold the land and other assets and went to India. One neighbour stated that Sri Sharma had drunk all his

movable and immovable property. But his neighbours do not know that he has leprosy, although we found one neighbour that did, so we assume that there are likely to be more who really know. We cannot however say that he has gone to India because of the disease. It seems clear that the reason he has left home is financial. He has absolutely no assets left (at home).

His mother said that Sri Sharma has never written a letter home. This was confirmed by a neighbour.

9. *Sri Jaisi.*

The patient had gone to India. The information given by his wife and some neighbours is given below.

According to his wife:

Seven years before he had got the disease and after 18 months treatment in the village he was no better. One time when a neighbour's harvest was being gathered (a community cooperative work) he was coming home (after dark) carrying a lighted torch and burned his hand. Because of this he had an injury and was not able to eat (with his hand) so began to eat with a spoon. On seeing this his neighbours began to talk about him (criticise him).

Before this his hands and feet used to tingle. He used to say to his children, the outside of my left foot does not feel pain, see, I can burn it with fire, and he used to pinch the flesh hard. After such burnings blisters used to come and the resultant wounds take a very long time to heal. After this his wounds got somewhat better after he went to Kathmandu for their treatment. His wife's younger brother told him about Green Pastures Hospital and he then went there.

Before this he took his wife to India for treatment to her eye injury. At that time she said he should get treatment for his wound, but he did nothing.

His wife said that after getting treatment from Green Pastures he got better and also found out about his disease. One time when he was about to leave to go to Pokhara to get his medicine he called on a friend and had a chat. This friend told him that he could also get leprosy (KUSTHA ROG) medicine at a Terrai town nearby. On hearing that he went there. Then, when he was going to India he said, I will get medicine on the way. But he forgot his ticket (PURJI) and sent to his wife to ask her to send it to him in India, which she did. He went to India for work after taking treatment from Pokhara for a few months. His wife said she does not know whether he is taking medicine or not now. (In the opinion of the interviewers he is very likely still taking treatment.)

Some of his fingers and toes are possibly damaged. He apparently went to Tansen for treatment when his hands and feet began to tingle. But they did not get better with that medicine. He went to Pokhara because of that, 18 months after he got the disease. His wife did not say plainly that her husband had leprosy. She said they have no social but do have economic problems.

According to his older brother:

When we first spoke with him he hesitated and said he knew nothing. But the next day, when he understood the matter it became apparent that he had known of his brother's disease from the beginning. It is understood from him that his brother's staying in the village had not brought any problem (prohibition). When asked why the disease came he replied that it is the fruit of KARMA, or fate (the result of action which accompanies the transmigration of the soul).

According to one neighbour:

A teacher in the village said that Sri Jaishi's disease is the same as that of one damai who had gone to Green Pastures Hospital and got better, therefore he had advised Sri Jaishi to do the same.

Almost all have said that the patient has gone to India to earn because of economic difficulties. But the interviewer thinks there must be a real reason for the patient to go to India when he is older. He wonders if perhaps it is because the patient is an orthodox Brahmin and he would be required to live separately in his village?

It takes three days to get to Pokhra from this village and there are no problems with rivers. There is Health Post one day's journey away.

10. *Sri Sharma (2)*. Interview 40.

We could not meet the patient in his village. In the village were his father and mother and one backward younger brother. From a maternal uncle, Sri Timilsina, it was found that Sri Sharma (2) had moved to Pokhra about eight years before. He told that Sri Sharma (2) works in an office there. His uncle said that he found out Sri Sharma (2) had a disease about two years before when he had met him in Pokhra. At that time his face was black and when he asked him about it Sri Sharma (2) had explained that his skin was tingling and that he was taking medicine for that, the medicine took a long time but the doctor said that when it was finished his skin would lose its black again.

Having learned from his uncle that he was living in Pokhra we went there, found and had a discussion with him there.

According to Sri Sharma (2) about eight years ago he obtained a position in administration in industry. There seems to be no social or economic problem. He says that no one knows that he has got leprosy (KUSTHA ROG). He had bought a house and land in Pokhra and is living there permanently.

While talking to Sri Sharma (2) he went outside to comfort his daughter who was crying. We asked his wife about her husband's disease. She said ; "My husband has not got the disease that spoils hands and feet and eyes!" From this we gather that she does know because at that time the matter of leprosy had not come up in our conversation.

On the matter of medicine Sri Sharma (2) said that after taking medicine his disease had neither got worse nor better. His hand used to and continues to tingle. He is afraid of deformity but

thinks it can not happen to him. When speaking of stopping the treatment he talked about being sick of the medicine because it had to be taken for such a long time. Even though he did not say it clearly it is the opinion of the interviewer that he really stopped the medicine because of the black discolouration resulting from it. He said he had not taken medicine from any other place. His physical condition seems normal.

Summary of Interviewee 39's story and analysis of interview June 25th 1991

From the Out Patient Card at Green Pastures Hospital:

63 year old male registered 44.2.25 Voluntarily.

Head of household

contacts not listed

No known index case

Type BB

Smear 1+

Disability WHO grade 2

Presenting symptoms (Problems)

Plaques

weak eye lid

patch

paralysis

ulcer

swelling

Reversal Reaction

Duration of symptoms, 2 months

Treatment

MBMDT 1

Dexamethazone course

Attended:

13 times in 5 months (weekly for Dexo)

Result:

RR better

Eye lid weakness better

Stopped treatment one month after Dexo course completed.

Total monthly doses of MDT taken: 5

Rx Completing date: 44.6.21

Listed as Out of Control 'OC' at Green Pastures.

Listed as Cohort member for Study.

Staff Interviewer sent to find and interview him 47.7.17

Patient met, examined and interviewed

Physical examination:

Few small illdefined non-anaesthetic skin patches present.

Three nerves enlarged

Old large scar on (R) knee

Both feet dry and anaesthetic

(R) eyelid slightly weak

Interviewer Report

His family knows about his disease but no one in his community knows. He was found living together with his family. Their economic condition was good. To go to Pokhra from his home takes one day. There did not seem to be any difficulties on the road; it is an easy road. They had not let anyone know that he was taking medicine from Green Pastures, and when the time came for him to take medicine for the last time (the end of the Dexo course) the thought occurred that perhaps he would be OK without

taking the medicine. After the medicine had made him black his neighbours began to ask but the patient did not explain about the disease.

Analysis of the interview transcript translation.

The problem with this interview is mentioned by the Interviewer above. The patient seemed to be afraid of the interviewer and his companion and when the recorder was on would only answer giving short 'yes' and 'no' replies. I would add that he repeatedly denied knowledge of matters to which he later admitted and also as mentioned above would not admit on tape a matter that he had admitted in conversation before the taping began. This reluctance to admit matters on the (tape) record and the fact that the tape recorder was 'lost' at this house makes one wonder whether he and his wife were really worried that his disease would become known to his neighbours or that the tape would be used against him in some way. The tape recorder disappeared from the verandah where the patient and the interviewer were sitting. Fortunately for the research the recorded tape itself had been removed before the machine was set down.

The interview is long, 225 questions were asked and the interviewer only obtained some useful material after persistent and skilled probing.

The story emerging from the Interview Transcript Translation

This man returned home from service (with the Indian Army) on a Pension. After returning home a patch on his knee, which had been slightly swollen while he was in India, became painful, swelled more and eventually became infected. The time for going one day's journey to Pokhra to receive his (annual) pension came. He and his wife went to Pokhra. While in the bazaar he made enquiries about a 'big' hospital and was told to go to the Green Pastures Hospital. At the same time his wife had been enquiring and she took him to the (government) hospital where they at first refused to see him but then gave him a paper (of referral) to go to the hospital (down the valley), Green Pastures. There he was examined thoroughly without his clothes and given only tablets. He stayed two days. He was told his disease was like KOR (LEPER). Upon learning this his heart 'hurt inside' and his 'mind was lost a little'. He was told to come each week.

While at first saying that no one knows about his disease he eventually said that his son and daughter-in-law had come to know and that an village elder also went with him to Green Pastures. This was not at the initial visit but on a subsequent one. (It would not be unusual for a village elder to accompany a leprosy patient to the hospital to enquire about his likely infectivity and what the village should do in relation to the patient. Whether this was so in this case is not known. However, from what he said, it seems that his social relationships - smoking with other villagers, admission to their kitchens and them eating what he gives - were still intact.)

He began to go to Pokhra weekly and neighbours began to question him about his unusual, frequent trips. As he took the medicines his skin became discoloured (black) as he had been told by the health worker. He had also been assured that the black would go away when he finished the medicine. His neighbours also began

asking him about his colour. He admits to being worried about his family and children, and afraid of what would happen to him. He had seen the sorts of people at the hospital with no hands and feet. He also lives near MALUNGA, a Government Leprosy Asylum, and would probably be familiar with the fate of the inmates. He was able to tell where leprosy treatment was available near his home.

It is not quite clear at what stage the LAMA (traditional healer) was called from a neighbouring village. It may be either just before he got treatment from Green Pastures or just after he returned from one visits there. The LAMA informed them that the HOUSEHOLD GOD was disturbed (had come upon him) and that to settle the god rice and milk must be given by an unmarried man. One of his sons did that and as a result he received relief.

After completing the medicine that required weekly visits to Pokhra he was unable to return for his monthly appointment because he was needed at home for the urgent maize planting. When this was finished he thought about going but did not because he was better, because he could not be on time and was therefore afraid of being 'told off' (as he had heard happen to others who were late), and possibly because he was anxious about his black colour and about people finding out about his condition. He felt good about himself at the time of interview and stated that he was cured, both by perhaps the medicine, and by the PUJA (religious ceremony of worship) to the household god.

All together he is recorded as attending thirteen times within a four month period. Each time this involved a two and a half hour walk to the motor road, waiting for the bus which was often crowded and finding a seating a problem; and a three to four hour ride. He would have to stay overnight if he arrived in Pokhra after two o'clock or so as the clinic at Green Pastures might not see patients who come after that time. The next day he would attended the clinic and may have spent one to two hours there. If he was seen early he could get a bus and reach his home that evening but most likely he would have had to wait until the next day to return home. Each visit then meant two to two and a half days away from home. In four months he would have been away from home 26 to 35 days or about one third of the time.

In short:

To this patient his *problem* was a swollen knee patch with pain (Reversal Reaction). After 13 time-consuming and costly weekly journeys to Green Pastures, 13 weeks of steroid therapy and doing the prescribed (and costly) PUJA to the household god this was *better, he felt relief*. Along with this his skin had become *black* from the medicine and his *neighbours had begun asking* about his colour, and his frequent trips away. He had told no one about his condition and did not want them to know. He had seen patients at GP with *no hands and feet* and this made him afraid. His duty to his family and community kept him *at home for the maize planting* so he could not keep his appointment on time. He had overheard patients who were late for their treatment at GP receiving a *telling off* by the staff. He anticipated this same *threatening* if he went back late. He did not go.

It is of interest that this interview illustrates the kind of deception or *concealment* that Miller (1990) describes from his work in a village in a neighbouring district. In the life of village Nepal there is little or no privacy, everyone knows and is curious about what others are doing, planning and so on. There are elements of family life, such as a member having leprosy, which must be kept quiet so various techniques are used to keep others from knowing and perhaps using the information against the family, from manipulating to their disadvantage. Here "concealment is self-defence." (Miller 1990:145) This technique is ... "especially used when people decide on a course of action that flies in the face of society's norms." (op cit. p.160) This concept helps us to understand what is happening when the patient does not want to admit matters on the record. It also applies in his keeping his condition quiet and his anxiety when he became black and was away so often. Concealment is achieved either through *keeping silent* or through *deception*, that is "*saying something* and not saying what (it is) wished to keep secret." Thus words which are not literally true are used as a *shield*, to protect the family reputation, prestige and wellbeing.

Miller also refers to the use and misuse of words, and reluctance to have them recorded (on paper). Perhaps the fear of the tape recording can be explained too. In the largely non-literate society of village Nepal Miller maintains that

Face-to-face oral communication can be adjusted and fine-tuned to a situation in a way that written communication can never be. Words in black and white (or on tape) cannot be manipulated so easily (by the speaker) nor is there any way to foresee and take into account the moods and dispositions of those to whom the communication is addressed at the moment they receive it. (1990:144)

In his conversation with the interviewer before the tape went on the patient talked more freely, but one suspects warily as he was addressing an educated, literate high caste man and an outsider. The dominant social group in Nepal, the Brahmins and Chhetri, some of whom form the literate few in some villages, may be seen to have a remarkable eloquence with spoken words but also to have the ability ... "to manipulate written documents, if they wish, to the disadvantage of the illiterate many." So in his oral communication the patient was able to use his skill and techniques of concealment, adjusting his words to suit the situation and audience. But when faced with the tape recorder, and the consequences, non-adjustable words potentially manipulable by others, he became very cautious. Miller (p. 144) states that "Stories of this ... manipulation [of written documents to the disadvantage of the illiterate] are familiar to villagers who are thus understandably wary of the *written* [recorded] word.

APPENDIX C

FIVE ITEMS OF BACKGROUND TO LEPROSY AND NEPAL

- I The Legal Code in effect in 1990 mentions leprosy.
- II The Religious Story giving cause, consequences and cure for leprosy.
- III Ayurvedic texts mentioning leprosy; description and remedies.
- IV Tibetan Medicine and leprosy.
- V On Consulting Astrologers.

I MULIKI AIN The Legal Code of Nepal, in effect in 1990.

Marriage A rough translation.

The marriage shall be voidable, if the marriage is made by misrepresentation with a man or woman who is dumb or suffered from leprosy (Kustharog), or disabled or blind or sex organ-less (impotent) or lunatic and suffered with epilepsy, Rs 500 will be fined to marrying man or woman and the contracting party.

II **SWASTANI BRATKOTHA** A Hindu Religious Book of stories and moral lessons, read aloud daily for a month each year by devout religious Hindu families in Nepal. The illustrated edition this translation is made from was revised and published in April 1990. Some people in the Bazaar were asked; "Are these just stories from 'then' or did they really happen?" "Oh, they really happened!" was the reply. This is the book referred to by some of the interviewees when asked where their 'problem' came from.

The story contained here, emphasis added, gives the cause, consequences and cure for leprosy. One wonders if it is a 'cautionary tale' for ensuring compliance with prescribed religious practices and accepting prevailing social hierarchies. Perhaps leprosy was the worst thing that could be experienced by anyone so became the consequence of inappropriate behaviour? Was the threat of becoming leprous a means of social control? Answers to these speculations are not likely to be found. What is certain, however, is that the concept of leprosy resulting from 'sin in a former life' was quite common among the interviewees.

Below are extracts of a translation of part of the Swastani Brat Kotha (Hindu religious book read annually in many families).

Part of 26th Chapter

After that she (Chandrawati) reached a big forest when she departed. In the forest a couple of deer and other wild life were enjoying the cool place; birds such as swans were enjoying the pond; the forest was decorated with flowers such as rhododendron and different fruits and plants; there was the sweet musical sound of bees buzzing, as such lonely place they saw. Some angels had joined together to worship God Shree Swastani, and then the bearers asked the Queen, as they were hungry, if they could go a little way to get something to eat, and they asked her to wait for a while. They went near the angels to find out what was happening; and asked them who they were, where they were from, which God they were worshipping. They replied that they were worshipping and fasting for Shree Swastani. "We are angels of heaven" they said. They heard such from them and the bearers asked if they could join them. When they agreed, the bearers were pleased and said, "But we have

nothing for the prayer". The angels allowed them to worship and pray to Shree Swastani.

They offered some money which they had got as their wages from the King. After they finished worshipping, the angels gave them prasad. Whoever worships Shree Swastani and fasts for her, or keeps the storybook at home, or hears the story, will have peace throughout his life and can go straight to heaven. They were pleased with the bearers and blessed them and went to heaven. And the bearers went to where Chandra Wati was waiting.

The end.

27th Chapter

Kumarjee addressed Agust Muni. After that the bearers said to the Queen, "We beg your pardon because we saw the angels from heaven who had been worshipping Shree Swastani; we also joined them so it became late. We have brought prasad for you too; please accept it." When she heard that from the bearers she got very angry and scolded them wildly, saying, "Leaving me alone in this dreadful forest, you went to worship. Is this the duty of a servant? Does that fast give you the bread and butter? Who is she? Where does she live? I haven't even heard her name. You didn't listen to my orders. I'm in a hurry to reach there. You are in the forest; if you were in the palace I would have killed you all." After saying this, she jumped from the planqueen and snatched the prasad from their hands, spitted and stamped on it and threw it away. "Will you do this again? Take me quickly." The poor bearers were afraid and with tears in their eyes took the name of "Shree Swastani" and carried the planqueen and started off from there. There was a river near Lawanny called Shalli River. Due to the hatred of "Shree Swastani" there suddenly came thunder and a stormy wind and heavy rain. Thus the bridge broke and Chandra Wati with the bearers fell off the bridge and the bearers straight away went to heaven. Whereas Chandra Wati, having been rude (dishonoured) to "Shree Swastani", remained there.

After that the water from the Shalli River stopped flowing and the fishermen were surprised and took a message to the King Nava Raj, saying "The Shalli River has stopped flowing. We haven't seen this any time before but now we have seen it with our own eyes. Think you of something." Hearing this from the fishermen, the King called the Prime Minister and told him what he had heard from the fishermen and ordered a net to be thrown to find out whether there was any human being there. Hearing this from the King, the fishermen threw the net and Bharmani Chandrawati was caught and came out. When she came out with the net she was suffering from *leprosy and her legs and hands were damaged due to leprosy*. She was unconscious, covered with mud and because of this she seemed like wood. No-one could recognise what it was and threw it on the bank of the river. So the fishermen repeated this process of throwing the net and going into the water to find out, but could not find anything there. Taking this message, they came to the King. After this King Nava Raj himself went and said, "Hai ganga! Why are you not flowing? Are you not happy with me?" Saying this he offered the milk of a cow. After this the river started to flow again. And after this the King went to the palace and Chandra Wati

Bramani lay beside the Shalli River and was suffering from different kinds of diseases from moment to moment. One day she felt very hungry, but finding nothing to eat she took mud in her hand to eat but the mud changed into stone, and when she wanted to eat that stone it changed into bone, and again the bone changed into ash and when she began to eat that even the wind came and blew it away. *Due to the hatred of Shree Swastani*, she had to bear different sorts of unbearable things like thirst, hunger etc. And she lay there beside the river.

After that King Nava Raj called the Bramins and gave a donation and gave them a party. Bhramins from Aganipur also went to the party in the King's palace. Chandra Wati saw them and asked them, "Who are you? Where are you going?" The Bhramins answered her saying, "We are Kapil Named Bramins; we are going to Lawannya to King Nava Raj's palace; he has invited all the Bhramins from his country for the party. Hearing this Chandra Wati says, "Hey, Bhramins, I have not eaten for many days. Bring some food for me and you will be blessed." The Bhramins replied, "What's going to happen in the palace? We may or may not be able to bring some; we cannot guarantee it. If they give us some, we shall bring it, but don't be too hopeful." Saying this, they left for Lawannya. Nava Raj gave all the Bhramins enough food to eat but the Bhramins from Agnipur seemed not to be satisfied. Queen Goma realised that and asked them why they were wanting to eat more. They replied, "We took delicious food by the grace of the King and were satisfied. But as we were on the way here, on the bank of the Shalli River a woman suffering from leprosy, without hands and with damaged legs, saw us and enquired where we were going. We told her that we were Bhramins and were going to take delicious food in the King's palace. She told us to bring some food for her because she had not taken any food for a long time and she was very hungry. Queen Goma then ordered the cook to give the Bhramins as much as they could carry. When the cook took the food from the store, the cook found that all the food had disappeared. Finally she gave them the food which had been cooked for herself. The Bhramins were ashamed of themselves. As soon as they left, everything filled up as it was before.

The end.

28th Chapter

After that the Bhramins went to Chandra Wati with the food and she asked whether they had brought the food for her or not. "Because of you" they replied, "we were ashamed; all the food in the store had disappeared. You are a sinner, This is the rice we brought; wash your hand and eat, seeing you are like this we felt sorry for you. We want to suggest that you fast for "Niranjan Nirakar Shree Swastani. After that you will be free from sin." Saying this, the Bhramins then left. Chandra Wati went crawling to the Shalli River. Suddenly the water flow stopped. She cried and tried to eat without washing, but the rice she wanted to eat changed into ash. The ash even she wanted to eat, but it was blown away by the wind. She lay there for one year.

One full moon night the angels from heaven came down to the Shalli River to take a bath for the Swastani fast. Chandra Wati

saw them and asked who they were. "I cannot move my body" she said. "Nobody gives me food. What have I done? How to be cured?" The angels replied, "Hey, sinner, we are angels from heaven sent by Indra and we have come here to fast for Shree Swastani. Seeing you we felt sorry. You fast for her too. Then you will be free from sin." Chandra Wati thought "I haven't committed any sin except throwing away the prasad of Swastani. I was too proud of myself so I got these troubles." She determined to fast for Swastani and asked the angels to tell her about the system of the fast. The angels said that after bathing and contracting the mind towards Shiva, she should fast for one month. Listen to the story of Swastani with the different kinds of flowers and fruits. Write 'Omkar' on R.C. and bath with the Ganga Jal and put a garland on it. Then ask for the blessing; don't forget to give the prasad to your husband; if there is no husband give it to your son; if there is no son give it to your son's friend. If you can't find anyone throw the prasad into Ganga. Doing this all your sin will disappear."

Chandra Wati started to pray from the bottom of her heart. She bathed every day in the Shalli River and started devoting herself to Shiva. Slowly her sin started disappearing and *leprosy was being cured from day to day.* After a month the angels again came to the Shalli River. Chandra Wati told them that she had been doing what they said but she did not have anything to make the prasad. The angels told her to use sand if she hadn't anything else. When she brought the sand to make prasad it was changed to all those things which were required for Swastani fast. Seeing that she felt very grateful and reported to the angels. When the angels saw her she had already turned into a beautiful woman. The angels were surprised and said, "We were addressing you as a sinner before, but now we will name you as **Punya Wati**. And they let her join the fast. She was very grateful and started saying, "Goddess Swastani, I was very proud and I threw the prasad away and hated you. I am very sorry about that. Hey, Lady of the Land, you are the true Goddess. Your being is unbelievable. You live in every human heart. You are the Bhrama, Bishnu and Mahesh. You are in the earth, wind and sun in heaven."

"The way one should pray to you, even the Bhrama and Naag cannot manage, how then can I? It's impossible for me, but still listen to my prayer and forgive my sin." After completing the fast, the angels left Chandra Wati and went to heaven. She had all those prasad in her hand but couldn't decide to whom to give them. She prayed for a blessing, that she might meet her husband soon. She threw all the prasad to the Shalli River. After completing the puja business she was blessed and recovered her precious human life. Finding all this so true, she really thanked the Goddess Swastani.

The end.

III AYURVEDIC MEDICINE – the traditional ancient system of Hindu Medicine Along with other traditional forms of medical practice in Nepal the Ayurvedic System is widespread. There is a training system and network of treatment centres across the country as well as efforts to integrate some of the Ayurvedic remedies into the Basic Health Service of the Ministry of Health.

Ayurveda is the science of health and healing and of life practiced by the ancient Aryans. This science is based on Atharava-veda, one of the oldest scriptures of the Hindus, about 3,000 years old. ... Ayurveda is not considered to be merely a compendium of *therapeutics based on herbal, animal and mineral resources* of the world. It is claimed to be a *philosophy of life and living*; its **object** is to *counteract imbalance of the three essential elements*. These three elements, *vata* (air), *pitta* (bile) and *kapha* (phlegm), constitute the *tridosh* from which the human body originates; this *tridosh* regularises the normal working of the human body. (Dastur, J.F. 1960, reprint 1988, *Everybody's Guide to Ayurvedic Medicine. A repertory of therapeutic prescriptions based on the indigenous medical system of India*. D.B.Taraporevala sons & Co. Private Ltd. Bombay, India, Introduction).

The concept of balance and hot and cold are found here as well as in the Tibetan "health through balance". The "air", "bile" and "phlegm" concepts and classification have their roots in the ancient classical world of Greece and Rome. Today in the west there are remnants of this system in some writings on personality when people are said to be of a 'phlegmatic' or 'choleric' disposition and so on. The characteristics of phlegm and bile are used to describe such kinds of personality.

While the ancient Hindu scriptures preserve these concepts for present-day practitioners of Ayurveda and those who use their services, said to be "at least one fifth of the human race" (Dastur 1960), another author (Gupta 1986) claims that they cannot be satisfied by mere translations. He states that these translations are not in touch with the real need of the people and that

there is much in them that does not stand careful sifting. We can only come in sight of a few isolated truths after journeying through an enormous mass of rubbish. (Gupta, K.R.L. Second Edition 1986. *Hindu Practice of Medicine*. Sri Satguru Publications, Delhi, India, Preface).

Both these authors provide a listing of ailments and remedies, lists of plants, and descriptions of how to prepare the herbal treatments. Both also deal with Leprosy in some detail. The concepts and remedies are given here for interest and completeness.

Gupta provides a short description of Leprosy as well as listing remedies.

TREATMENT OF LEPROSY

Leprosy commences first in the skin, and gradually extends deeper and deeper, affecting the different essential parts as flesh, blood, fat etc. Thus, like the small roots of the Banian tree, which are at first confined to the surface, they advance deeper and deeper, until they extend over the whole body. In the first stage, when it is superficial, the use of proper diet and medicines may cure it; but when it has extended to a greater distance, the difficulty of curing it becomes much greater.

Diet. In leprosy, flesh, with the exception of that of wild animals, and gleaginous articles of food are not to be used; as also hard food, milk, curdled milk, certain kinds of pulse; sour articles or sweet, prepared from sugar-cane. Improper and indigestible articles of food, or eating too often of roasted or heating food are to be avoided, and also sleeping in the day time, and connexion with women. Good and old rice is to be used with barley, flour, and peas (*mugh*) boiled in water, and mixed with the leaves of *nimba*. Such vegetables as contain a bitter principle are useful. In other cases, barley is recommended to be steeped in cow's urine for a night then dried in the sun. This is to be repeated for seven days, then fry it, and some of it is to be taken every morning with a decoction of the following bitters,

Kantikari, (Solanum Jacquini,) and
Nimba, (Melia Azadirachta, etc.)

Prepared oils are to be used to anoint the body with.

The ulcers are to be cleansed with astringent decoctions; with an oily preparation called Vajraka, and a paste or liniment of the aragbadha (Cassia fistula). The water with which the person washes or bathes should be impregnated with *khaya*, catechu, which should also be mixed with drinking water.

In the beginning of the disease purgatives and emetics are first to be administered. If the leprosy is confined to the skin evacuant medicines, and smearing the body with different sorts of medicines are of use. If confined to the blood it is to be purified by evacuants, smearing the body with proper medicines, drinking bitter and astringent decoctions, and venesection.

When confined to the flesh the remedies are the same as those of blood, with tonic tinctures of various kinds. *When confined to the fat it is incurable; but the progress of the disease may be checked by proper diet and medicines, especially tonics. When to bones are affected it is incurable, and should not be treated.* (Italics are mine).

When marrow is diseased the man will soon die. In the seven forms of leprosy, besides emetics, purgatives, gysters, suppositories, with errhines are to be used. If these five forms of medicine have been employed without effect, the case may be considered as hopeless.

When *air* produces leprosy, prepared ghee with astringent

tonics are to be used; when *phlegm*, emetics; when *bile*, blood is to be removed from the person, and purgatives are to be used.

The following mixtures are much recommended in leprosy. Take equal parts of;

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| <i>Meshashringi</i> | (<i>Asclepias germinata</i> , etc.) |
| <i>Shwadangshtra</i> | (<i>Flacourtia catafracta</i>) |
| <i>Gulancha</i> | (<i>Minispermum glabrum</i>) |
| <i>Shangashtha</i> | (<i>Leea hirta</i>) |

mix with *Panchamuli*.

This mixture consists of equal parts of the bark of

| | |
|-------------------|------------------------------------|
| <i>Bilwa</i> | (<i>Aegle marmelos</i>) |
| <i>Sanala</i> | (<i>Bingonia indica</i>) |
| <i>Gambhari</i> | (<i>Gmelina arborea</i>) |
| <i>Patala</i> | (<i>Bignonia Sauveolens</i>) and |
| <i>Ganikarika</i> | (<i>Premna spinosa</i> .) |

These medicines are to be boiled in water, shaken, mixed with ghee, and boiled down till the watery part has dissipated. This to be taken internally, mixed with oil, rubbed over the body. In other cases the ghee is prepared in the same way with

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|-------------------|---------------|
| <i>Bhallataka</i> | (Marking Nut) |
| <i>Abhaya</i> | (Myrobalan) |

and a verifume plant called *brianga*. It resembles black-pepper, is prepared as above, and used for the cure of all different forms of leprosy.

Blood-letting is used frequently in the cure of leprosy, and is abstracted from different veins. When prominent patches form, scarifications, leeches or caustics are to be used.

Various medicines are recommended for rubbing over the body. They are usually of a stimulating nature. The following is one of these. Take of

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| <i>Haritala</i> | (Yellow arsenic) |
| <i>Manahshila</i> | (Red arsenic) |
| the juice of Madar, (<i>Arka</i>) | |
| a kind of horse-radish called <i>Sigur</i> or | |
| <i>Shobhanjana</i> black-pepper, and the seed of | |
| Sesamum, (<i>Til</i>), | |

mix together, in equal parts. These are to be rubbed with water, and applied to the surface affected. There are seven other varieties of such mixtures. The following is recommended. Take of the leaves of *Cassia fistula* (*sondal*), and mix them with butter-milk, and rub it over the diseased part, particularly where there are tubercles. Others recommend the froth of the sea (*samundra-phena*), after it has been dried, to be rubbed over the diseased part.

The following may therefore be considered as the best means of curing leprosy. Use freely catechu by mixing it with the water of the patient's bath, in his drinks, food and medicine, while he avoids animal food, wine and intercourse with women. When the disease is subdued, use purgatives freely to prevent a relapse. With these means, certain diet, wearing clean clothing, and a proper degree of exercise is to be used. Such treatment will generally cure the disease: especially if emetics are given every fortnight, purgatives

every month and venesection twice a year. Two tolas of the powder of tumeric in cow's urine are to be taken at the same time, every day for one month; and every third night an errhine is to be exhibited.

The following mixture is also recommended. Take the bark of the *nibma* tree, the leaves of a kind of cucumber commonly called Palwal, (*Palta*) the leaves of solanum Jacquini, (*Kantikari*,) *Minispermum glabrum*, (*Gulantha*,) with the bark of *Justicia ganderussa*, (*Basaka*,) of each ten *pols* mix them with 64 seers of water; and boil to 16 seers. Remove it from the fire, and add four seers of ghee by degrees, and again put it on the fire until the water is dissipated. To this medicine add the;

| | |
|------------------|------------------------------------|
| <i>Haritaki</i> | (Paste of Myrobalan) |
| <i>Bibhitaka</i> | (<i>Terminalia belerica</i>) and |
| <i>Amlaki</i> | (<i>Phyllanthus emblica</i>) |

each two *pols* (eight tolas make one *pol*), 5 tolas, and 2 *masas*, and 7 *ratas*, are to be added. The whole is to be mixed in a mortar, to which ghee is to be added; it is again to be placed over the fire for a short time, and when mixed, it is then to be strained through a cloth.

This taken internally is said to cure leprosy, the 80 diseases produced by deranged air, the 40 diseases of bile, and the 20 diseases of phlegm. It is also useful in bad boils, worms, piles, and the five kinds of cough. Other mixtures equally efficacious in curing numerous diseases are recommended. These vaunted qualities of certain mixtures is to encourage the patient, and the practitioner; and their inefficiency explains the numerous other mixtures which are recommended as substitutes.

Should worms form in leprosy ulcers, a paste made of the bark of *Nerium odorum* (*Assamara*), and the seeds of a verminfuge plant called *biranga*, with cow's urine, is to be applied to the sore.

Gupta thus provides a glimpse into the intricate world of the Ayurvedic system and perhaps a 'tongue in cheek' comment on certain claims of curing mixtures. The Ayurvedic approach here is a kind of global one, where not just the disease 'bugs' are targeted, but many aspects of life and living.

By way of contrast Dastur provides a list of local applications and internal mixtures with very little comment.

LEPROSY

1. The paste of the roots of *Cassia sophera* (*kesunda*) made with *conjee* is a very useful local application.
2. The seeds of *Cassia tora* (*chakund*) are soaked in the milky juice of *Euphorbia neriifolia* (*tholar*) for some time; these seeds are ground into a paste with cow's urine; this paste is applied over the affected parts.
3. The root-bark and flowers of the Cotton Plant made into a paste with water are locally applied.
4. The powder of the *panchang* of the Neem tree is a very efficacious dust for leprosy ulcers; these ulcers can be also washed with the decoction of the panchang.

5. The poultice of the macerated bark of *Albizia lebbek* (sirisha) is applied to the diseased parts of the skin.
6. The decoction of the Arjun Tree (arjuna) or of *Terminalia tomentosa* (asana) or of catechu is very efficacious for washing the ulcerous skin.
7. The *swaras* of the fruit of *Momordica charantia* (kereiala) is locally applied.
8. The medicated oil or *teila ghrita* prepared by boiling sesame oil with the roots and the *swaras* of the leaves of *Vitex negundo* (indrani) is applied over the affected part.
9. The paste made of *Rubia cordifolia* (manjishta) with honey and butter is a useful ointment.
10. The ointment made of realgar (manahcila), orpiment (ala), black pepper, mustard oil and the milky juice of *Calotropis gigantea* (akda) is applied over the diseased skin.
11. The ointment made of *rasot* and the seeds of *Cassia Tora* (chakund) with the juice of wood apple (kawitha) is an efficacious local application.
12. The paste made of the leaves either of *Cassia fistula* (amaltas) or of *Solanum nigrum* (kakamachi) or of the Oleander (kanera) with whey is very efficacious for the cure of leprosy skin; before the ointment is applied the skin is anointed with mustard oil.
13. The ointment prepared by mixing one drachm of the liquid extract of *Centalla asiatica* (brahmi) with some bland oil is a very efficacious local application in leprosy.
 - i) Instead of the ointment the poultice of the fresh leaves may be used.
 - ii) The powder of the plant is used as a dust over the affected parts.
 - iii) The infusion of the plant is used for bathing the affected parts.
14. The paste made of Conessi bark (kurchi) and the pods of *Pongamia pinnata* (karanja) is applied over the affected parts.
15. The paste made of corianda seeds (dhanya) and the *Costus* (kusht) is applied over the diseased parts.
16. The decoction of one of the following drugs is an efficacious bath for patients suffering from leprosy:
 - i) The *panchang* of Oleander;
 - ii) The *panchang* of *Cassia fistula* (amaltas);
 - iii) The bark of the Dita Bark Tree (saptaparna);
 - iv) *Pongamia pinnata* (karanja).
17. The powder of a hundred Neem leaves is given with water regularly every day; this treatment has to be continued for six months.
18. The mixture of the powder of neem leaves and chebulic myrobalan (harada) or emblic myrobalan is given regularly every day for more than a month.
19. The medicated oil or *teila ghrita* prepared by boiling sesame oil with equal quantities of the *swaras* of the leaves of *Vitex negundo* (indrani) is given.
20. *Centalla asiatica* (brahmi) is a very efficacious drug in leprosy.
 - i) The leaves picked from the fresh plant are dried in shade; the fine powder of these leaves is given in doses of 3 to 5 grains three times a day.
 - ii) The fluid extracted of the leaves is given in doses of 1 to 5 drops to begin with; the dose is gradually increased to 15 drops a day.

- iii) The leaves are given in the form of syrup; 90 grammes of powder of the shade-dried leaves are boiled with a quart of water till the liquid is reduced to one pint; 2lb of sugar are added to this decoction which is again boiled over a slow fire till a syrup is formed; one drachm of this syrup is given at first; the dose is gradually increased.
- 21. The root of *Plumbago zeylanica* (chitraka) is given in 25 grain doses with water in leprosy.
- 22. The swaras of the bark of the Dita Bark (saptaparna) is given with milk.
- 23. Chaulmoogra oil is very efficacious in leprosy; it is given in doses of 10 to 20 drops after meals; it is also used externally on the affected parts; the treatment is to be continued for three months.

Discussion:

This latter was used by scientific medicine before the advent of specific antibiotics for leprosy which have been developed in the last 40 or so years.

IV LEPROSY IN TIBETAN MEDICINE

The following is extracted from:

Donden, Yeshi. Ed and Translated by Jeffrey Hopkins. 1986 *Health Through Balance; An Introduction to Tibetan Medicine*. Snow Lion Publications. Ithaca, New York USA. p. 35 ff.

The Tibetan tradition uses NINE BRANCHES OF UNHEALTHY BODY (TRUNK)

- 1 Cause
- 2 Condition
- 3 Entrance
- 4 Locations
- 5 Pathway by which it spreads
- 6 Time of arising
- 7 Fatal effect, result
- 8 Side effects resulting from treatment
- 9 Consolidation, cold or hot.

In this publication leprosy is not dealt with systematically but the following has been gleaned from various parts of the book. Diagnosis in the Tibetan medical system is primarily and supremely by touch, by feeling the pulse. In describing healthy and unhealthy pulses the author mentions; 'the leprosy pulse beat is limping and quivering, as if shivering. "Limping" means that at the end it contracts like a person limping.' (p.95&96) Further in the same section he deals with kinds of pulses. Among these are Spirit Pulses. To put the mention of leprosy in context it is worth quoting two paragraphs from pages 102 and 103.

In brief, if the pulse is bulky, prolonged, and unclear and is a right side spirit pulse, it should be identified as a male spirit pulse. If the pulse is subtle, short, and unclear and is a left side spirit pulse, it should be identified as a female spirit pulse. In another way, the king spirit that is the custodian of property is responsible for spirit-created wind disorders. Violent spirits and violent evil serpent spirits are responsible for spirit-created pulmonary inflammations. Female spirits called ma-

mo-jang-men are responsible for spirit-created bile disorders. *Mischievous serpent spirits and earth-owner spirits together are responsible for spirit-created dropsy, tumors, gout, ulcerous growths, lupus, and leprosy.* Once the physicians have identified the spirits that are involved, they suggest remedies such as the conduct of rituals, giving food offerings, having rites of exorcism performed by competent lamas, receiving blessings, making donations to religious persons, gaining merit through giving to the destitute, and so forth. In relation to treatment among the measures listed is behavior, and specifically occasional behavior mentions the following on pages 148&149;

There are thirteen types of occasional or temporary behavior to be considered: hunger, thirst, vomiting, yawning, sneezing, breathing, sleeping, clearing mucus in the throat, expelling saliva, defecation, expelling gas, urination, and emitting semen. You should not forcefully suppress any of these thirteen. *Not allowing yourself to vomit will lead to a loss of appetite, difficulty in breathing, a disease that involves swelling of the face and hands, sores, itchiness, sores that will not heal, leprosy, disorders of the eyes, and also a tendency to get the common cold again and again. If you come to this disorder, the remedy is to fast, to inhale the smoke of aloewood and sandalwood, and to drink frequently small amounts of fluids such as water with honey in it.*

Leprosy is also mentioned in passing in the section dealing with special topics where a question is asked about hereditary factors and the reply is; 'We do consider leprosy to be within families.' Finally in further discussion on the causes of diseases leprosy is again mentioned on pages 197&198.

...the causes of these diseases derive from the three basic mental afflictions of desire, hatred, and ignorance. Although mainly the causes are indeed the three mental afflictions just mentioned and the three humors - wind, phlegm and bile - the *primary contributing conditions are to be found in seven types of organisms living in our bodies. The first is a blood organism that has no legs; it is extremely difficult to see - I think that it would be difficult to see even with a microscope. It is with the blood and thereby moves to all important points of the channels. This is one condition for the arising of all these types of extremely degenerative, malignant disorders; it also acts as a cause for leprosy.*

Thus we are provided with some glimpses of the perceptions of leprosy from the point of view of Tibetan Medicine. The applications of remedies fitting the understood cause is also illustrated, particularly the 'spirit-caused' ailments among which leprosy is listed. In our work so far we have not come across anyone who has admitted to undertaking these remedies after leprosy was diagnosed. However we have not interviewed anyone who is predominantly Buddhist either.

The concept revealed in the latter quote, "organism of the blood" is of particular interest as a contributing condition for getting leprosy. It would be interesting to know if this is an old or recent concept and whether it has a matching and different remedy

concept.

In summary we see here that leprosy is caused by mischievous serpent spirits and earth-owner spirits, that the forceful suppression of vomiting may lead to leprosy or other illnesses, that there is a primary contributing condition, a blood organism; and that this disease derives from the basic mental afflictions of desire, hatred and ignorance. Finally that it is considered to be within families.

It is also of interest to note that leprosy is associated with conditions like; dropsy, tumors, gout, ulcerous growths, lupus; swelling of the face and hands, sores, itchiness, sores that will not heal, disorders of the eyes and so on. Even though leprosy is not described for us in this publication these associations provide an idea of the picture that leprosy brings to mind for these people.

COMMENTS ON KLEINMAN'S EMs AND THE DERIVATION OF SAME

When I first read Kleinman's work and saw his EM outline my reaction was that even though he was dealing with other world views and their ways of explaining their episodes of illness he structures the EMs on a framework which to me seemed to emanate from a bio-medical perspective. Is this an incongruity?

For this study I have used Kleinman's outline, namely

- 1 etiology
- 2 time and mode of onset
- 3 pathophysiology
- 4 course of illness, degree of severity acute, chronic, impaired
- 5 treatment

The Tibetan tradition uses NINE BRANCHES OF UNHEALTHY BODY (TRUNK)

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- 6 Time of arising
- 7 Fatal effect, result
- 8 Side effects resulting from treatment
- 9 Consolidation, cold or hot.

In more detail these are;

1. Cause
2. Condition. Factors which help the cause to ripen, or manifest, as a disease.
3. Entrance. Stages through which the disease develops and spreads in various parts of the body once the conditions effect the ripening of the cause.
4. Locations. The disease then localizes itself in various sites and settles. (The sites where diseases of predominant wind, bile or phlegm settle.)
5. Pathway. The pathways through which diseases of wind, bile and phlegm spread in terms of the seven physical constituents and organs. (Physical constituents; Nutritional essence,

- Blood, Flesh, Fat, Bone, Marrow and regenerative Fluid.)
6. Time of arising. How certain factors of age, season, time of day, and locality promote specific humoral disorders.
 7. Fatal effects or results. Nine categories of incurable, terminal situations.
 8. Side effects resulting from treatment. e.g. a side effect of treating a wind disorder may be that a bile disorder is produced.
 9. Condensed. Ultimately all diseases can be condensed into two categories, cold and hot disorders, p. 30-32. DISEASED BODY TRUNK

(1) *Causes Branch*

1. Desire (peacock)
2. Hatred (snake)
3. Obscuration (pig)

(2) *Condition Branch*

1. Time/Season
2. Spirits
3. Diet
4. Behavior

(3) *Entrance Branch*

1. Skin
2. Flesh
3. Channels
4. Bone
5. Vital Organs (Solid Organs)
6. Reservoir Organs (Hollow Organs)

(4) *Location Branch*

1. Brain (Upper Body)
2. Diaphragm (Middle Body)
3. Hips, Base of the Spine (Lower Body)

(5) *Pathways Branch*

Wind Disorder

1. bone
2. Ear
3. Skin
4. Heart, Life Channel
5. Large Intestine

Bile Disorders

6. Blood
7. Perspiration
8. Eye
9. Liver
10. Gall Bladder and Small Intestine

Phlegm Disorders

11. Nutritional Essence
12. Stool, Urine
13. Lung, Spleen, and Kidneys
14. Stomach, Urinary Bladder
15. Nose, Tongue

(6) *Time of Arising*

1. Old age
2. Adult
3. Child
4. Cold (wind)
5. Dry (heat)
6. Humid
7. Summer (rainy season)
8. Autumn
9. Spring

(7) *Fatal Effects*

1. Exhaustion of life span, karma, merit
2. Disorder increasing regardless of medication
3. Non-effectiveness of diet, behavior, medicine, accessory therapy
4. Wound in vital organ
5. Severance of continuum of wind in central channel
6. Untreatable heat disorder
7. Untreatable cold disorder
8. Physical constituents cannot accept the medicine
9. Life force stolen by spirits

(8) *Side effects Branch*

1. Bile arising from wind alleviation
2. Phlegm arising from wind alleviation
3. Bile arising from unsuccessful treatment of wind
4. Phlegm arising from unsuccessful treatment of wind
5. Wind arising from bile alleviation
6. Phlegm arising from bile alleviation
7. Wind arising from unsuccessful treatment of wind
8. Phlegm arising from unsuccessful treatment of wind
9. Wind arising from phlegm alleviation
10. Bile arising from phlegm alleviation
11. Wind arising from unsuccessful treatment of phlegm
12. Bile arising from unsuccessful treatment of phlegm

(9) *Condensation Branch*

1. Cold (wind, phlegm)
2. Hot (blood, bile)

It comes back to the concept of balance or equilibrium.

V. ON CONSULTING ASTROLOGERS

Notes from Warren W Glover (1974) *Semantic and Grammatical Structures in Gurung (Nepal)*. Summer Institute of Linguistics University of Oklahoma, Norman. pp206 - 211 Appendix

This is an explanatory discourse used to illustrate grammatical structures but included in my work as an example of the *social control present in the Gurung society*.

"Today was the day when we Hindu castes eat the firstfruits of MARSII rice. But, er, because (they) said today was an auspicious occasion, that is to say, day, the astrologers (did). Previously the astrologers had looked at the days.

Then, before last Sunday the eleventh, in the evening, (they) said to the crier, 'Go and give the word in the village. Go to the middle and cry (it)' the astrologers and village leaders (said).

Then the crier came to the middle of the village and cried, (he) cried saying, 'Tomorrow, Monday the twelfth, get a bunch of MARSİ rice.'

Then in the morning of Monday the twelfth at eight o'clock the people of the households which planted MARSİ rice, from each household one person, went to their respective fields and plucked of their own field a head of marsi rice and a head of chrysanthemum.

Then, on Tuesday the thirteenth, (they) again let the crier cry out, the astrologers and the leaders (did). The crier again came to the middle of the village and cried, saying 'Tomorrow, Wednesday the fourteenth, at nine o'clock in the morning (is) the eating of the firstfruits of the MARSİ rice.'

Then everybody, this morning at nine o'clock, ate the firstfruits. The custom of us Gurungs is thus.

And another matter, if (you) plant MARSİ rice and CINIYA rice on the fifth day of ASAR the CINIYA rice will ripen on the twentyfifth of ASOJ, (and) the MARSİ rice on about the twentyninth (or) thirtieth of KARTIK.

That being the case, also for us Gurungs, when (we) are building a house (one) must look for an auspicious occasion. If (you) should ask, 'Who looks for the day?' the astrologers (do). In placing the foundation of the house (one) looks for an auspicious occasion.

Again another matter, however (things) may be, when building a shed, (or) moving a shed, (one) moves (it) under obligations (i.e. of looking for an auspicious occasion).

Again another matter, when (we) hold a wedding also, an auspicious day is needed.

Again another matter, when girls are first born, within three days (we) give (them) a little ragged dress. Then they wear that ragged dress continually. And (they) wear ragged dresses up to three or four years of age. (We) look for a day, with the astrologers. They (we) give the girls a cape and skirt.

Then another matter, when soldiers are going back for duty (lit. to be on parade) in India, again (they) look for a good day with the astrologer. Saying, 'What day must (I) make (my) departure?', (they) ask (him). Then the astrologers answer, 'On a particular day, such and such a time, (you) must go.'

APPENDIX D

RESEARCH INSTRUMENTS

- I Community Survey Questionnaire.
- II Staff Questionnaire - Hospital
- Field
- III Patient Interview Topic List
- IV Cohort Form

I COMMUNITY SURVEY FORM

Nawal Parasi Community Survey 1990. *English translation of the FORM used, being an adaption of the 1980 form.*

Q1. What are the health problems which trouble you most in your village? (write at least four according to priority)

- 1.
- 2.
- 3.
- 4.

Q2. Of which disease are you most afraid? (put two lines under the main one and one line under the next)

1. Cholera
2. TB.
3. Leprosy
4. Small Pox
5. Malaria
6. Whooping Cough
7. Other

Q3. (a) What is the cause of leprosy or what makes leprosy come?
(Write the answer first)

(b) Are any of the following causes of leprosy?

| | YES | NO | DON'T | KNOW | COMMENTS |
|-------------------------------|-----|----|-------|------|----------|
| 1. Hereditary | ! | ! | ! | | ! |
| 2. Fate, (i) this life | ! | ! | ! | | ! |
| (ii) previous life | ! | ! | ! | | ! |
| 3. Curse from god | ! | ! | ! | | ! |
| 4. Evil spirits | ! | ! | ! | | ! |
| 5. Germs | ! | ! | ! | | ! |
| 6. Bad food | ! | ! | ! | | ! |
| 7. Bites from certain insects | ! | ! | ! | | ! |
| 8. Comes by itself | ! | ! | ! | | ! |

Q4. How do you recognize leprosy?

Q5. For what reasons are you afraid of leprosy?

| | YES | NO | DON'T | KNOW | COMMENTS |
|--------------------------------|-----|----|-------|------|----------|
| 1. Deformity of hands and feet | ! | ! | ! | | ! |
| 2. People won't touch you | ! | ! | ! | | ! |
| 3. Painful | ! | ! | ! | | ! |
| 4. Contagious | ! | ! | ! | | ! |
| 5. Isolation from the village | ! | ! | ! | | ! |
| 6. Other reasons | ! | ! | ! | | ! |

Q6. What are the signs and symptoms of leprosy?

| | YES | NO | DON'T | KNOW | COMMENTS |
|---|-----|----|-------|------|----------|
| 1. Ulcer | ! | ! | ! | | ! |
| 2. Do other diseases cause ulcers? | ! | ! | | | ! |
| 3. Deformed hands and feet. | ! | ! | ! | | ! |
| 4. Do other diseases cause this?! | ! | ! | | | ! |
| 5. Swollen face | ! | ! | ! | | ! |
| 6. Does the face swell in other diseases? | ! | ! | ! | | ! |
| 7. Patches (on the skin) | ! | ! | ! | | ! |
| 8. Do other diseases cause patches? | ! | ! | ! | | ! |
| 9. Numbness and loss of sensation. | ! | ! | | | ! |
| 10. Do other diseases cause this? | ! | ! | | | ! |
| 11. Other | | | | | |

Q7. Can leprosy be cured? (mark one of the following)

1. Always WHY?
2. Sometimes
3. Never
4. Don't know
5. Partially
6. Write any comments

Q8. How is leprosy cured?

| | YES | NO | DON'T | KNOW | COMMENTS |
|-----------------------------|-----|----|-------|------|----------|
| 1. By puja and making a vow | ! | ! | ! | | ! |
| 2. By Lama-Jhakri | ! | ! | ! | | ! |
| 3. Medical treatment | ! | ! | ! | | ! |
| 4. Pilgrimage | ! | ! | ! | | ! |
| 5. Eating good foods | ! | ! | ! | | ! |
| 6. Other | | | | | |

Q9. (a) VIGNETTE ONE

A woman felt a sharp pain in her foot and found it difficult to walk. One evening when she found it difficult to bear the pain she poured boiling water over her foot and then slept. In the morning there was a big blister on her foot. When her husband asked her about it she told him what she had done. Her husband took her to the medical shop where they diagnosed leprosy.

1. What would her husband do?
2. What do you think her husband should do?
3. What would the woman do?
4. What do you feel the woman should do?

(b) The woman was brought to the hospital and there she began to get regular leprosy treatment and treatment for her wound. One day the hospital discharged her saying that her disease was completely better, but there was still a small ulcer left on her foot. She returned to her family and stayed there

1. How do you feel about that?

(c) After some months her ulcer began to grow bigger so she came back to the hospital again. She returned home after it healed to some extent. But this problem came repeatedly, again and again. The inside of her foot began to be really spoiled. The doctor told her she would have to have her foot cut off. After this treatment was carried out and she was healed she returned home once again.

1. What will happen to her in her home now?
2. What will her village neighbours say?
3. How will her husband treat her?

Q10. (a) VIGNETTE TWO

One day a father took his daughter to the Health Post for a check-up. There he saw a Poster on the wall and began to read it. The early signs and symptoms of leprosy were written there. He realized that what was written there fitted with his own body description so he suspected he might have leprosy. He showed himself to the Health Worker and was examined. He started taking medicine regularly.

1. What would he do when he went back home?
2. Would he tell his family about his condition?

(b) After three months of regular treatment he began to get a fever, swellings with red raised patches, his body was very painful and he became very sick.

1. What should he do?
2. What would his community feel?
3. What was happening to him?

(c) He went to the hospital and got better after treatment. Villagers found out about his coming and going to hospital and they discovered he was suffering from leprosy. The rainy season came. All the people had to plant their fields. He needed their help as usual with planting his fields too.

1. What would the villagers do?

Q11. VIGNETTE THREE

In one family a girl had got leprosy and her family had treated her secretly and she became well. When it came time for her marriage her father did not tell the husband's family about her leprosy past. She was happily married.

1. What will happen to that girl now?
2. How do you feel about it?

Q12. Have you seen or heard about anyone with leprosy within the last year? What was done with them?

Comments about circumstances of the interview.

Age:

Sex:

Caste:

Signed:

Date:

Sampling Section:

II STAFF INTERVIEW QUESTIONS - HOSPITAL.

1. What are your responsibilities in relation to leprosy patients?
2. Who has the responsibility for making the diagnosis of leprosy?
3. How is the news of the diagnosis of leprosy given to the patients?
4. How do they usually react to the news?
5. What sort of patients, in your experience, are most regular on their treatment?
6. What sort of patient come once for treatment and never come back?
7. What is taught to leprosy patients about leprosy?
8. What is taught to leprosy patients about treatment?
9. What is taught to leprosy patients about reaction?
10. Which patients are taught about reactions ?
11. What is taught to leprosy patients about self care?
12. What results of this teaching have you observed ?
13. What are the main reasons for patients not continuing treatment in your thinking.
14. Before you came to work here what sort of disease did you think leprosy was ?
15. a. What changes have occurred in your thinking about leprosy after you have worked for some time ?
b. How long have you worked here ?
16. Were you afraid when you first came here ?
17. What were you afraid of ?
18. Are you still afraid ?
19. Why ?
20. How would you describe leprosy, what kind of disease is it ?
21. What is a "leper" - describe.
22. What are the duties of a "leper"?
23. Have you got any friends who are leprosy patients?
24. Nowadays what does your community think about leprosy?
25. What does your community say patients must do?
26. What is reaction?
27. What sort of patients get reaction?
28. What does reaction result in?
29. What are the signs of "active" disease?
30. In your thinking does leprosy sometimes not get better? Why?
31. From your experience how much does the black from Lamprene worry patients?
32. When patients are admitted to hospital for the first time do you see them going through stages of adjusting? What stages? How long does it take?
33. Do new inpatient learn some things from old inpatients which make your work easier or more difficult? If so what are they?
34. What sort of patients get infected ulcers?
35. What is the treatment for ulcer?
36. a. How long have you worked with leprosy patients?
b. Have you had special training in leprosy care? If so how long was the training? and how long ago was the training?
c. Have you had training in general medical matters too? If so how long and how long ago?

II cont. Field Staff Questions on meaning of Nepali Terms.

1. Do people in your area understand the terms Kushtharog and Kor to mean the same?
2. Do people in your area understand the terms 'Leprosy' and Kushtharog to be the same?
3. Do people in your area understand the terms 'Leprosy' and Kor to be the same?
4. In your opinion is:
Leprosy the same as Maharog?
Leprosy the same as Kor?
Leprosy the same as Kushtharog?
Maharog the same as Kor?
Maharog the same as Kushtharog?
Kushtharog the same as Kor?
Kushtharog the same as "Leprosy"?
5. What is the meaning of the term Kor to the people in your area?
6. What is the meaning of the term Kushtharog to the people in your area?
7. What is the meaning of the term "Leprosy" to the people in your area?

III PATIENTS INTERVIEW TOPIC LIST

Explanatory models (After Kleinman, 1980) and *Illness (Sickness) Career* (After Stafiliou-Rothschild 1970 and Twaddle 1977)

1. etiology
2. time and mode of onset
3. pathophysiology
4. course of illness - degree of severity
 - type of sick role - acute, chronic, impaired.
5. treatment - patient expectation
6. The problem
 - its name
 - its recognition
 - how and by whom
 - from health to illness
7. Help seeking
 - the decision
 - where, what, when
 - before diagnosis
 - how diagnosis arrived at
8. Impact of diagnosis of leprosy
 - how they felt at first & now
 - what they did
 - signs of depression?
9. Community expectation
 - attitude
 - action
10. Family situation and history of leprosy?
11. Cost of attending - financial, in time, socially.
12. Stigmatization - by self, and/or others.
13. Roles - adopted, changed.

IV Cohort Form HEALTH EDUCATION IN LEPROSY CONTROL IN NEPAL
(August 1990)

FORM 1. PATIENT CLINICAL INFORMATION FROM RECORDS OF SELECTED CENTRES

1. ID District (see separate list of HMG district codes) CODES

Centre

Card number for centre patient

2. Cohort Serial Number

3. Ethnicity Caste name

Bhramin/Chhetri 1

Low 2

Ethnic (Hills) 3

Ethnic (Terai) 4

Newar 5

Gurung 6

Muslim 7

Other 8

4 Address Panchayat WdNo Village

5. Major source of Income..initial ..current

6. Who knows why/where they have come neighbours 0

most of family 1

spouse/parent only 2

no-one 3

7. Family position 1= son in extended head 0

mother-in-law sub-head 1

wife in nuclear dependent 2

2= daughter-in-law unknown 3

child, servant

8. Family contacts number of persons in house

how many examined

how many new cases found

OMSLEP/FIRST REGISTRATION

9/1 Date of registration Nepali yr mt dy

10/2 Form of Leprosy

I 1

TT 2

PB BT 3

MB BT 4

BB 5

BL 6

LL 7

N 8

UNKNOWN 9

11/3 Mode of detection

voluntary 1

referred/notified 2

survey mass 3

contact 4

group 5

unknown 9

Medium through which detected

radio 0

poster 1

patient 2

pt acquaintance 3

other 4

unknown 9

Contact (Index case known?)

Yes 1

no 2

| | | | |
|---|---------------------------------|-------------------|---|
| <i>Re-admission</i> | | Relapse after MDT | 1 |
| | | after Mono | 2 |
| | | Re-entry | 3 |
| | | Transfer in | 4 |
| 12/4 Sex | | Male | 1 |
| | | Female | 2 |
| 13/5 Age at detection | | 0-14 | 1 |
| Year of birth | | 15 + | 2 |
| 14/6 Bacteriology highest reading | (highest BI | | |
| | not done or → unknown | | 9 |
| 15/7 Disability | maximum according to WHO | 0-1-2-3 | |
| (# nerves | degree weakness |) unknown | 9 |
| (initial extent, # sites involved eg. hands feet eyes | | score 0 to 6 | |
| 16 Presenting symptoms | patch | | 0 |
| | nodules | | 1 |
| | parasthesia | | 2 |
| | anesthesia | | 3 |
| | nerve pain | | 4 |
| | paralysis | | 5 |
| | ulcer | | 6 |
| | ENL | | 7 |
| | swelling | | 8 |
| | reversal reaction | | 9 |
| Duration of symptoms on diagnosis in months | | | |
| 17/10 Year and month or follow-up | | | |
| 18/11 Form of leprosy | PB | | 1 |
| | MB | | 2 |
| 19/12 Treatment/date begun | | | |
| | MDT PB | | 0 |
| | MDT MB1 | | 1 |
| | MDT MB2 | | 2 |
| | DDS | | 3 |
| | LAM/DDS | | 4 |
| | ETHIO/ISOPRO | | 5 |
| | RIFA | | 6 |
| 20/13 Treatment attendance record | regular | | 1 |
| total monthly doses | irregular | | 2 |
| total months registered | zero | | 3 |
| percentage | surveil | | 4 |
| | unknown | | 9 |
| 21/14 Clinical activity/year end status | active | | 1 |
| | inactive | | 2 |
| | doubtful | | 3 |
| | unknown | | 9 |
| Year End Status | treated | | 1 |
| | completed treatment during year | | 2 |
| | Relapse during surveillance | | 3 |
| | surveillance | | 4 |
| | unknown | | 9 |
| 22/15 Bacteriology | highest BI | | |
| | not done/known | | 9 |
| 23 Complications | none | | |
| | plantar ulcer | | |
| # months after treatment began | orchitis | | |
| | lamprene discolouration | | |
| | nasal collapse | | |
| | hoarse voice | | |

24/16 Reaction

Type I (Reversal) 1

Type II ENL 2

none 3

unknown 9

24/17 New disability

weak nerves

degree of weakness

yes 1

no 2 →

unknown 9 →

25 Hospitalization

reason

not 0

medical 1

Rehab. surgery 2

infected surgery 3

ulcer 4

reaction 5

other 6

frequency - how many times

duration - in months

steriod courses - how many

antibiotic courses - how many

26 Late - how many times

- action taken none 0

late letter 1

home visit 2

both 3

- reception upon return late penalty Rs 1

'row given' 2

both 3

- result regular since 0

late again 1

did not return 2

- reasons - list

- returned after first visit yes 0

no 1

27 condition at the end of time - physical

improved 0

unchanged 1

worse 2

- social improved 0

unchanged 1

worse 2

28 cost of attending - distance per vehicle Hrs & Km

- days away from home/work Rs per day

Number of times attending (self or Proxy)

Cost estimate per visit by # of visits

29/18 Off register

Released RFS 1

Died 2

Left 3

Transfer TT 4

Date Completed

Sign.

Comments

कर्मचारी प्रश्नावली

१. कुष्ठरोगी बिरामीहरू प्रति तपाईंको जिम्मेवारीहरू के के हुन् ?
२. कुष्ठरोग पत्ता लगाउने जिम्मेवारी कस्को हो ?
३. कुष्ठरोग पत्ता लागेको खबर बिरामीलाई कसरी भनिन्छ ?
४. त्यस्तो खबर सुनेपछि उनीहरूले प्रायजसो कसरी प्रतिक्रिया गर्ने गर्छन् ?
५. तपाईंको बिचारमा कस्ता किसिमका बिरामीहरूले सबभन्दा नियमित उपचार लिने गर्छन् ?
६. कस्ता किसिमका बिरामीहरू यहाँ एकपटक उपचारको लागि आएर फेरी कहिल्यै आउँदैनन् ?
७. कुष्ठरोगी बिरामीलाई कुष्ठरोगको बिषयमा के के सिकाइन्छ ?
८. कुष्ठरोगी बिरामीलाई उपचारको बिषयमा के के सिकाइन्छ ?
९. कुष्ठरोगी बिरामीलाई रियाक्सनको बिषयमा के के सिकाइन्छ ?
१०. कुन बिरामीलाई रियाक्सनको बारेमा सिकाइन्छ ?
११. कुष्ठरोगी बिरामीलाई आफ्नो हेरचाहको बिषयमा कुन कुराहरू सिखाइन्छ ?
१२. यी सिक्नाहरूबाट तपाईंले के के नतिजाहरू देखेनुभएको छ ?
१३. तपाईंको बिचारमा बिरामीले लगातार उपचार गर्नु छाड्नुको मुख्य कारणहरू के होला ?
१४. तपाईं यहाँ काम गर्नु आउनु भन्दा पहिला कुष्ठरोगलाई कस्तो किसिमको रोगहोला भनेर बिचार गर्नु हुन्थ्यो ?
१५. क) तपाईंकोमा भएको कुष्ठरोग प्रतिको बिचारमा तपाईं याहाँ केही समय कामगरी मकेपछि कस्तो परिवर्तन आयो ?
१६. ख) तपाईंले याहाँ कामगर्नु भएको कति वर्ष भयो ?
१७. पहिलो पटक तपाईं यहाँ आउदा डराउनु भयो की ?
१८. तपाईं के संग डराउनु भयो ?
१९. अरौं पनि तपाईंलाई डरलाग्दो ?